RESEARCH REPORT

Cultural validation of the Positive Stigma Inquiry (PSI)

By measuring leprosy-related stigma among community members in Nepal

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Summary

Introduction

Health-related stigma is defined as a process in which persons with certain health conditions face adverse perceptions and attitudes from society. Therefore, health-related stigma scales can be used to assess the levels of stigma, although the predominantly negatively phrased items raise concerns. The literature emphasizes the importance of a health-related stigma measurement tool comprised of positively or neutrally phrased questions, which may prevent the reinforcement of negative attitudes among participants. Therefore, a prototype called the Positive Stigma Inquiry (PSI) was developed by NLR and it measures health-related stigma among community members and healthcare workers. Two commonly used generic stigma instruments, the Explanatory Model Interview Catalogue Community Stigma Scale (EMIC-CSS) and the Social Distance Scale (SDS), were used as a source for the development of the PSI. However, the PSI has yet to be validated in a field context. Therefore, this study focuses on the cultural validation of the PSI in the field of leprosy in Nepal. Leprosy is a neglected tropical disease (NTD) that is highly endemic in Nepal, primarily affecting poor populations. This disease can cause physical impairments and those who are affected encounter social stigma, limiting their participation in society.

Objective and theoretical framework

This study's research objective is to prevent the reinforcement of stigma towards people affected by leprosy, by testing the cultural validity of a neutrally phrased instrument, the PSI, for measuring leprosy-related stigma in Nepal. Thereby, community members' perspectives regarding the PSI scale and its items will be examined, as well as the prototype's ability to measure stigma effectively. To assess the cultural validity of the PSI, a framework composed of the model of equivalence by Stevelink & van Brakel (2013), which uses newly developed definitions, combined with the quality criteria for measuring the psychometric properties provided by Terwee et al. (2007), was used in this study.

Methods

This validation study used a mixed-methods approach in an exploratory sequential manner. The qualitative (first) phase was aimed at assessing semantic, item, and operational validity of the PSI. In the quantitative (second) phase, psychometric properties of the PSI were analysed. In the first phase, semi-structured interviews were conducted with fifteen community members. Data derived from the semi-structured interviews were transcribed and translated into English and subsequently analysed using ATLAS.ti software. The PSI was then refined based on the qualitative results. The SDS (*n* = 100), the PSI (*n* = 100), and the EMIC-CSS (n = 50) were interviewer-administered in the second phase. Forty-eight repeat interviews for the PSI were conducted with the same participants after seven to ten days, to measure the reliability of the scale. Data collected from the quantitative phase were used to assess the

PSI's measurement validity, by analysing the following six psychometric properties: *internal consistency, criterion validity, construct validity, reproducibility, floor and ceiling effects, and interpretability*. Data from the SDS and EMIC-CSS were necessary for the assessment of *criterion* and *construct validity*.

Results

The qualitative results proved appropriate item and operational validity for the PSI. However, multiple adjustments to the scale were required to increase the semantic validity, since several PSI items were poorly understood by the community members. Examples were added to each PSI item to help low literate participants to better grasp the items. Item 8 *('Would the family member of a person with leprosy feel comfortable talking about it to their friends?')* was modified as it was challenging for respondents to distinguish between the affected person and his/her family members. In addition, Item 2 *('Would a community member feel comfortable living near a person with leprosy?')* was not paraphrased correctly by multiple participants, and therefore, the example for this item was adjusted to ensure correct interpretations.

The quantitative results demonstrated a low item-total correlation for Item 13 *('How often is the person's own name used instead of the name 'leprosy patient' when people talk about him/her?')*, and its removal slightly increased the Cronbach's alpha of the PSI. Based on this, Item 13 was removed from the PSI scale. Additionally, there was a statistically significant correlation between the PSI and SDS sum scores (r = 0.403, $p < 0.05$). However, no statistically significant correlation was observed between the PSI and EMIC-CSS scores. Nevertheless, the *construct validity* of the PSI was still rated positively because its correlation with the EMIC-CSS was nearly significant. The lower sample size for the EMIC-CSS could explain the non-significance, implying that a larger sample size could result in an improved assessment of *construct validity*. The remaining psychometric properties were also rated positively according to the quality criteria specified by Terwee et al. (2007).

Discussion and conclusion

Overall, we can conclude that the PSI is a culturally valid scale for measuring leprosy-related stigma among Maithili-speaking community members as all validity criteria (semantic, item, operational, and measurement) were met after making the necessary adjustments. This suggests that the PSI may be promising and applicable as a generic measurement tool for other stigmatised health conditions or cultures/languages. However, additional research with other target groups, stigmatised health conditions/neglected tropical diseases, and in other cultural/language settings, is needed to improve the applicability of the PSI. It is also crucial to validate the PSI in the Nepali language, making the scale applicable for the entire population in Nepal. More research is also necessary for conducting more EMIC-CSS interviews, in order to improve the assessment of *construct validity* of the PSI.

List of abbreviations

CARE	Consultation and Relational Empathy
CM	Community Member
EMIC	Explanatory Model Interview Catalogue
EMIC-CSS	Explanatory Model Interview Catalogue Community Stigma Scale
HCPA	Health Care Professional Attitudes scale towards persons affected by leprosy
HRQL	Health-Related Quality of Life
ICC	Intraclass Correlation Coefficient
IQR	Interquartile Ranges
LMIC	Low Middle-Income Country
NHRC	Nepal Health Research Council
NTD	Neglected Tropical Disease
PI	Principal Investigator
PSI	Positive Stigma Inquiry
PSSS	Participation Scale Short Simplified
QbyQ	Question-by-Question
RAs	Research assistants
RQ	Research Question
SAC	Scientific Advisory Committee
SALSA	Screening Activity Limitation and Safety Awareness
SARI	Stigma Assessment and Reduction Impact
SD	Standard Deviation
SDC	Smallest Detectable Change
SDS	Social Distance Scale
SEM	Standard Error of the Mean
WEMWBS	Warwick-Edinburgh Mental Wellbeing Scale

Table of content

1. Introduction

Health-related stigma is a social process that involves society's adverse perceptions on features of individuals, groups and identities linked to a certain health condition (Turan et al., 2019; Weiss & Ramakrishna, 2006). This process involves negative attitudes, values, and beliefs along with discriminatory behaviours, practices, and policies towards individuals affected as well as their families (Turan et al., 2019). It has been demonstrated that people with a stigmatised condition experience less opportunities in their lives (Akbari et al., 2023; Peters et al., 2017). This implies that stigma is a barrier in seeking healthcare, social relationships, and employment, which leads to limited participation in society (Hofstraat & van Brakel, 2016; Peters et al., 2017; Stangl et al., 2019). Stigma can be driven by, among others, fear of transmission, perceived unattractiveness, cultural values and beliefs, or a lack of knowledge (Sermrittirong & van Brakel, 2014; Stangl et al., 2019).

Stigma has a significant impact on the daily lives of people affected by leprosy, which is known as an NTD. Leprosy is caused by *Mycobacterium leprae* (Mitra & Mawson, 2017; van Brakel et al., 2019). This bacterium affects the nerves and may cause physical impairments, limiting activities that require the hands, feet, or eyes (Mahato et al., 2023; Romero et al., 2012). Leprosy is associated with poverty, which is why this disease is more common in tropical countries with a large proportion of poor people (Mitra & Mawson, 2017; van Brakel et al., 2019).

Nepal is a tropical country where leprosy is highly endemic, with approximately 3000 new cases reported yearly (Mitra & Mawson, 2017; World Health Organization, n.d.). In Nepal, leprosy remains feared and negative attitudes towards people affected are still prevalent among community members, who are the focus of this study (Adhikari et al., 2013; De Stigter et al., 2000; Marahatta et al., 2018; Peters et al., 2017). Community members may avoid people affected because of fear of infection and believe that the health condition might be associated to supernatural causes (Peters et al., 2017). The primary cause for this behaviour is a lack of awareness about leprosy or its transmission (Akbari et al., 2023).

Specifically visible impairments, such as skin lesions or wounds, are associated with high levels of stigma (Dijkstra et al., 2024; Hofstraat & van Brakel, 2016; Marahatta et al., 2018; van Brakel et al., 2019). Negative behaviour and the fear of being excluded from the community motivates people with leprosy to hide their condition from their environment (Adhikari et al., 2014; Marahatta et al., 2018). Concealing the disease, because of anticipated stigma, forms a barrier to seeking healthcare (Adhikari et al., 2014). Leprosy-related stigma may also lead to shame, issues in social relationships, employment, and food sharing (Peters et al., 2017). This has negative consequences on the socioeconomic status, physical and mental well-being and thereby the quality of life of individuals with leprosy (Marahatta et al., 2018; Peters et al., 2017; Thapa et al., 2023; van Dorst et al., 2020; van Netten et al., 2021).

To improve the quality of life, measurement instruments are essential for a better understanding of the stigma process, determining the level of stigma in a particular context and evaluating the effectiveness of interventions focusing on stigma reduction (van Brakel, 2006). Therefore, various tools have been established to measure health-related stigma. These tools focus on different health conditions, such as HIV or leprosy (Berger et al., 2001; Peters et al., 2017), and perspectives from different populations, such as affected individuals or community members (Bogardus, 1933; Weiss et al., 1992; Srinivas et al., 2018). Two commonly used instruments to measure health-related stigma are the EMIC-CSS and SDS.

In recent years, there is more awareness in literature about adverse terminology in existing health-related stigma tools (Peters et al., 2014). Experts expressed their concerns about the negative phrasing of the EMIC-CSS items, such as *'In your community, does [condition] cause shame or embarrassment?'* (Mol et al., 2023; Peters et al., 2014). Phrases like *'shame'* or *'embarrassment'* are negatively loaded and may unintentionally reinforce respondents' potential negative and insensitive attitudes towards affected people. It is crucial that stigma assessment tools should not cause discomfort regarding individuals with a stigmatised condition (Peters et al., 2014). To prevent reinforcement of stigma towards individuals with a certain health condition, stigma scales with positively or neutrally phrased questions are needed. The prototype PSI was recently developed by NLR, to measure stigma among community members and healthcare workers, using positively or neutrally phrased items. For developing the PSI items, the SDS was used since this scale consists of neutrally phrased questions. The EMIC-CSS was also used as a source for designing the PSI, because the SDS does not measure most aspects of community stigma, whereas the EMIC-CSS does (see *health-related stigma scales* in Chapter 2.2). However, the validity of the PSI has yet to be tested in a field study. To prevent biased findings and subsequently incorrect conclusions, it is critical to culturally validate new stigma tools (Peters et al., 2014). Therefore, cultural validation of the PSI in the context of health-related stigma is essential before the instrument can be applied in practice (Stevelink & van Brakel, 2013).

Hence, this study's research objective is to prevent the reinforcement of stigma towards people affected by leprosy, by testing the cultural validity of a neutrally phrased instrument, the PSI, for measuring leprosy-related stigma in Nepal. Herein, the research question of this study states: *To what extent is the Positive Stigma Inquiry (PSI) a culturally valid measurement tool for assessing leprosy-related stigma among community members in Nepal?* Therefore, the perspectives of community members regarding the PSI and its items will be studied, and to determine whether the prototype accurately measures stigma.

2. Contextual background

2.1 Leprosy in Madhesh province, Nepal

Nepal is a low-middle-income country (LMIC) and despite the government declared leprosy as no longer a public health concern in 2009, the country is still endemic for leprosy with approximately 3000 new cases reported yearly (Mahato et al., 2023; Taal et al., 2022). Leprosy remains high endemic in Madhesh province (40%), also known as Province 2 and is regarded as the poorest region of Nepal (Mahato et al., 2023; Shah et al., 2022). This study was conducted in the Dhanusha, Mahottari, and Sarlahi districts, located in Madhesh province in the Terai region of Southeast of Nepal. We collaborated with the Lalgadh Leprosy Hospital, which is located in the Dhanusha district. This was a suitable location to validate the PSI scale since the hospital has good relationships with communities in the abovementioned districts. According to the city population, Dhanusha has 867.747, Mahottari has 706.994, and Sarlahi has 862.470 residents (Population Statistics, Charts, Map and Location, n.d.). The number of new case detection for leprosy in the Dhanusha district is 38.66 / 100.000 population (Department of Health Services, 2023). The new case detection rate for leprosy in Mahottari and Sarlahi districts is not known.

2.2 Health-related stigma scales

Different tools have been developed to assess health-related stigma. For this study, two commonly used stigma scales have been utilised for the validation of the PSI. Before the PSI will be discussed, it is essential to first understand the origin and purpose of these health-related stigma instruments.

The Explanatory Model Interview Catalogue Community Stigma Scale

One frequently used example of a health-related stigma scale is the Explanatory Model Interview Catalogue (EMIC). This scale is developed to assess perceptions and beliefs in the field of leprosy and mental health in India and is derived from the explanatory models in Kleinman's study (Kleinman, 1980; Peters et al., 2014; Weiss et al., 1992). The development of the EMIC was driven by the knowledge gained from research focusing on how culture affects diseases and mental health in tropical countries (Weiss, 1997).

Based on the EMIC, the EMIC-CSS was established to assess the perception of participants regarding the behaviour of their peers towards people with stigmatising conditions (Appendix VI.I). The EMIC-CSS has also been used in the field of leprosy in different cultures and consists of fifteen items. This scale covers various facets of life that may be influenced by stigma (Ballering et al., 2019), such as concealment, avoidance, pity, shame, being made fun of, respect and marriage. The EMIC-CSS has been culturally validated in Indonesia by Peters et al. (2014) for the Stigma Assessment and Reduction of Impact (SARI) project and used in the study by Mieras et al. (2020) to measure leprosy-related stigma among community members in Nepal.

The Social Distance Scale

Another example of a health-related stigma scale is the Social Distance Scale (SDS), which has been developed by Bogardus (1926) (Peters et al., 2014). The SDS interview was originally established to assess acceptability levels of relationships or interactions between Americans and individuals with different ethnical backgrounds. Social distance can be defined as *"grades and degrees of understanding and intimacy which characterise personal and social relations"* (Park, 1923). The SDS includes a vignette and seven items reflecting different hypothetical situations with a person with the condition studied, such as renting a room, common place of work, neighbourhood, member of the same social circle, personal job brokering, marriage into someone's family, and childcare (Appendix VII.I). The interview starts with reading the vignette about a person affected by a stigmatised condition, for instance leprosy. Then, respondents can indicate the degree to which the interviewee wants to keep social distance towards the person described in the vignette using a Likert response scale. Social distance is interpreted as represented attitudes and emotions (fear) regarding the condition studied. This scale has also been validated in the study by Peters et al. (2014) and used in the study by Mieras et al. (2020).

2.3 Development of the PSI

The literature highlights the need for a health-related stigma scale that comprises positively or neutrally phrased items assessing all aspects of stigma. Since the SDS consists of neutrally phrased items, this scale was used as an example for the development of the PSI items. However, the SDS does not measure all components of stigma. The EMIC-CSS is a generic scale widely used to measure health-related stigma (van Brakel et al., 2019). Hence, the EMIC-CSS was also used as an example to develop the PSI since this scale measures most aspects of community stigma. In comparison to studies examining the perceptions of affected individuals or community members concerning health-related stigma, there is a lack of studies focusing on scales measuring healthcare worker stigma or perceptions of patients with stigmatised conditions. The PSI was developed to fill this gap. The PSI is a scale using only positively or neutrally phrased items aimed at assessing stigma among community members, with a sub-scale for measuring stigma among healthcare workers specifically (de la Paz, 2023). In this study, the focus will be solely on community members.

The EMIC-CSS and Health Care Provider's Attitudes scale towards persons affected by leprosy (HCPA) were used as a basis and adapted to develop the PSI with positively or neutrally questions (Srinivas et al., 2018; Weiss et al., 1992). The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) for instance, is composed of positively phrased scale items which assess mental wellbeing from a positive perspective, but it can also measure poor mental wellbeing (Tennant et al., 2007). It is essential that health-related stigma scales with positively or neutrally phrased items reflect the same experiences as negatively phrased stigma scales. Therefore, the PSI should have positive- or neutrally phrased items that do not have an impact on how participants perceive a certain health condition. Focusing simply on collecting positive experiences through positive phrasing may influence the outcomes (Mol et al., 2023; Reeves et al., 2022).

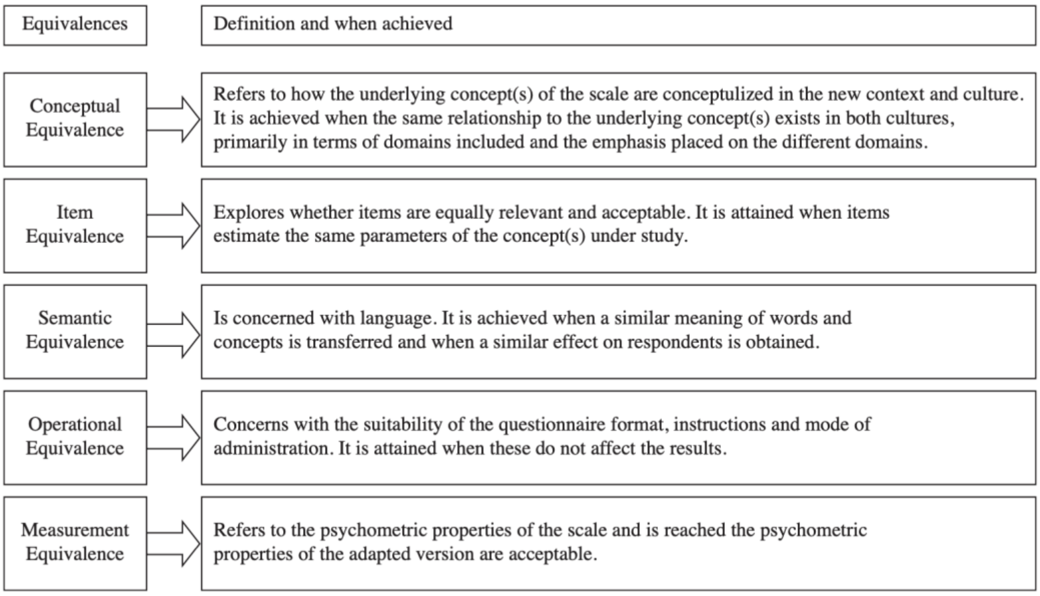
The PSI has been developed in consultation with various stigma experts from different parts of the world (de la Paz, 2023). The prototype measures health-related stigma among community members and healthcare workers and consists of eighteen items (Appendix V.I). The first thirteen items of the PSI are based on the EMIC-CSS and aim to assess stigma among both community members and healthcare workers. The remaining five items are based on the HCPA scale and aim to measure stigma among healthcare workers specifically. Moreover, the 5-point Likert scale format (None of the time (1), Rarely (2), Some of the time (3), Often (4), All the time (5)) originates from the WEMWBS. These answer options are widely understood across cultures and languages. During the development phase, an additional option – (0) I don’t know – was added to the response scale. Respondents are asked to select the option (0 to 5) that describes their perceptions regarding each item best (Tennant et al., 2007). Since this part of the study is focused on community members, only the first thirteen scale items will be included in the study, and the sub-scale targeting healthcare workers will be left out.

3. Theoretical background

Two theories – the model of equivalence and the quality criteria for psychometric properties of health-related instruments – will provide the theoretical foundation. These theories along with its relevant concepts will be discussed in the following section. Subsequently, the conceptual framework for this study is proposed, followed by the sub-research questions.

3.1 The model of equivalence

The model of equivalence by Herdman et al (1998) is a framework developed to assess different versions of one health-related instrument in a cross-cultural application. An example would be a validated English version of a stigma scale and a newly translated version in a local language. Equivalence represents the degree of similarity between the instruments among different cultures (He & van de Vijver, 2012). Cross-cultural validation is the *process* of determining whether instruments developed in one culture are applicable and equivalent in another (Huang & Wong, 2014). The cross-cultural validation process is essential because concepts such as stigma may be understood differently in another culture. This suggests that it is important to first assess the cultural validity of health-related instruments created in one culture but intended for use in another. The model of equivalence by Stevelink & van Brakel (2013) is used to assess the cross-cultural validation of instruments. This model is adjusted from the original model developed by Herdman et al. (1998) and consists of conceptual, item, semantic, operational, and measurement equivalences (Stevelink & van Brakel, 2013). These domains should be considered for achieving a cultural equivalence of the adapted instrument. Figure 1 presents the framework for the cross-cultural validation process, including the definitions of the different equivalences. Cultural equivalence is not indicated in Figure 1 but is defined as *"the extent to which an instrument is equally suitable for use in two or more cultures"* (Stevelink & van Brakel, 2013). The framework in Figure 1 is adopted from the study by Peters et al. (2017), and the definitions of the equivalences originates from Stevelink & van Brakel (2013). Additional discussions of the equivalence concepts are included in Appendix I.



Equivalences	Definition and when achieved
Conceptual Equivalence	Refers to how the underlying concept(s) of the scale are conceptulized in the new context and culture. It is achieved when the same relationship to the underlying concept(s) exists in both cultures, primarily in terms of domains included and the emphasis placed on the different domains.
Item Equivalence	Explores whether items are equally relevant and acceptable. It is attained when items estimate the same parameters of the concept(s) under study.
Semantic Equivalence	Is concerned with language. It is achieved when a similar meaning of words and concepts is transferred and when a similar effect on respondents is obtained.
Operational Equivalence	Concerns with the suitability of the questionnaire format, instructions and mode of administration. It is attained when these do not affect the results.
Measurement Equivalence	Refers to the psychometric properties of the scale and is reached the psychometric properties of the adapted version are acceptable.

Figure 1. Framework of the protocol for a cross-cultural validation process. The framework is adopted from the study by Peters et al. (2017), which derived the definitions from Stevelink & van Brakel (2013), adjusted from Herdman et al.'s study (1998).

Equivalence implies that the results from the PSI are comparable to another version of the same instrument, e.g., a translated version (Herdman et al., 1998). However, this is not applicable to this study because the original (English) version of the PSI has not been validated yet. Therefore, we cannot speak of semantic, item, operational, measurement, and cultural equivalence. For the purpose of this study, the term equivalence is altered into "validity" for each domain. The new concepts encompass conceptual, item, semantic, operational, measurement and cultural validity. The term validity is more appropriate to use and indicates the degree of how effectively an instrument assesses the parameters it claims to measure (Dunn, 2020). New definitions for the cultural validity domains were created together with the research team and are illustrated in Table 1. Herein, an adjustment has been made to the definition of measurement validity (see Table 1).

Table 1. Newly developed definitions of the cultural validity domains.

Type of validity	**Definitions**
Conceptual validity	'The extent to which the instrument reflects the underlying concept in the target culture, primarily in terms of domains included and the emphasis placed on different domains.'
Item validity	'All items are relevant for and acceptable to the target group and culture.'
Semantic validity	'The meaning of the words and expressions used in the items are appropriate and well understood without additional explanation.'
Operational validity	'The questionnaire format, instructions, mode of administration and response scales are appropriate and user friendly for the intended target group or culture.'

Measurement validity	‘The psychometric properties of the instrument meet the criteria specified by Terwee et al. (2007).’
Cultural validity	‘The extent to which an instrument is suitable for use in the target group and culture.’

3.2 Quality criteria for psychometric properties of health-related questionnaires

Various studies have suggested guidelines for evaluating health-related questionnaires. The Scientific Advisory Committee (SAC) of the Medical Outcomes Trust is a widely recognised criterion. However, these studies, including SAC, did not propose criteria for identifying good measurement properties (Lohr, 2002). Terwee et al. (2007) established a framework to measure the design, methodology, and outcomes of research focused on the development and evaluation of health-measurement instruments. The quality criteria are necessary to compare the content and measurement properties between existing questionnaires to define what the most effective tool is in a certain context.

The study by Terwee et al. (2007) proposes eight psychometric properties that are needed to achieve measurement validity, which are (1) content validity, (2), internal consistency, (3) criterion validity, (4) construct validity, (5) reproducibility, (6) responsiveness, (7) floor and ceiling effects, and (8) interpretability. *Content validity* refers to the degree to which the concept of interest is represented by the questions of the health-related instrument. *Internal consistency* measures the degree of correlation between the questions in an instrument; in other words, if items assess the same concepts. *Criterion validity* addresses the degree to which scores from a specific instrument matches the scores from a measurement tool that is considered as a golden standard. *Construct validity* refers to the degree to how scores from a certain instrument corresponds to other measures in a way that is compatible with theoretical hypothesis related to the concepts that are being assessed. *Reproducibility* involves the degree to which repeated tests among stable individuals yield similar results. This psychometric property distinguishes agreement and reliability as separate concepts. *Agreement* refers to how well repeated scores match each other when the test is performed twice on the same individual. It assesses measurement error. A small measurement error is important to distinguish clinically important changes from measurement error. *Reliability* refers to the extent to which a distinction can be made between persons/patients, regardless of measurement error. *Responsiveness* concerns the questionnaire’s ability to identify changes over time, regardless of whether these are minor. *Floor and ceiling effects* are present if ≥15% of the respondents reached the lowest or highest potential scores. This indicates the sensitivity of the instrument at the lower and higher end of its score scale. *Interpretability* is about assigning qualitative meaning to quantitative scores.

3.3 Conceptual framework

For this study, the model of equivalence by Stevelink & van Brakel (2013) (using the newly developed definitions from Table 1), is combined with the quality criteria for measuring psychometric properties provided by Terwee et al. (2007) (Figure 2). The combination of these two models (but using the cultural equivalence domains with its original definitions, instead of our newly developed definitions) has previously been used in the study by Peters et al. (2014), to measure leprosy-related stigma among community members in Indonesia, and in the study by Dijkstra et al. (2024), to cross-cultural validate two scales to measure mental wellbeing among leprosy-affected individuals in Nepal. Using this framework contributes to examining whether the PSI is a culturally valid and an effective measurement tool for assessing health-related stigma in the context of Nepal. The conceptual framework allows to develop the sub-research questions, the semi-structured interview guide and serves as a base for data analysis.

In this validation study, *conceptual validity* will not be tested because the concept of stigma and its domains has already been extensively studied in the context of Nepal (de Vos Klootwijk, 2019). Additionally, *responsiveness* will not be examined, due to the timeframe of this study. The psychometric property *content validity* has already been examined by other project team members to determine whether the PSI items represented the stigma domains described in the framework of Link & Phelan (2001). Since this was examined by other project team members, findings related to this property will not be discussed in this report.

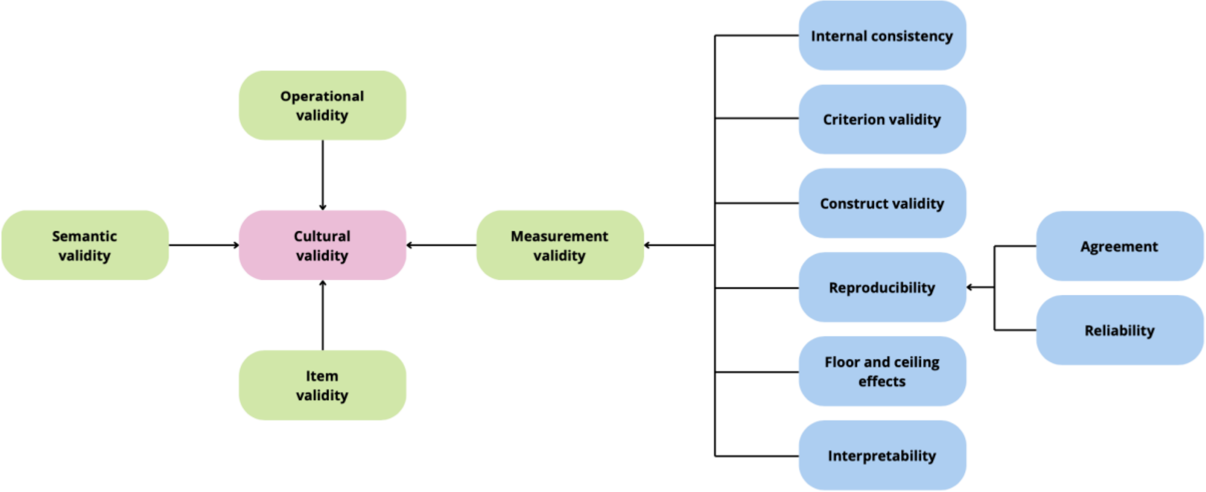


Figure 2. The conceptual framework of this study. This framework is adapted from the model of cultural equivalence by Stevelink & van Brakel (2013), based on Herdman et al. (1998) and the quality criteria for psychometric properties to evaluate *measurement validity*, Terwee et al. (2007).

3.4 Operationalisation of the conceptual framework

The cultural validity domains should be rated positively in order to determine whether the PSI is a culturally valid measurement tool for assessing health-related stigma. *Semantic validity* can be obtained when the language – meaning of words and expressions – used in the PSI items is understandable and appropriate for community members without further explanations. Then, *item validity* can be assessed and the items in the PSI should be relevant and not perceived as offensive by the community members in Nepal. Regarding *operational validity,* it is essential that the PSI uses an accessible and appropriate questionnaire format and response scale for community members, to ensure that these factors do not influence the scores of the respondents. *Measurement validity* is achieved when the psychometric properties *content validity, internal consistency, criterion validity, construct validity, reproducibility (agreement and reliability), floor and ceiling effects, interpretability* meet the quality criteria provided by Terwee et al. (2007). The EMIC-CSS and SDS were used as golden standards for the analysis of *criterion* and *construct* validity of the PSI. Subsequently, *cultural validity* is obtained when all domains (semantic, item, operational, and measurement validity) of the PSI are rated positively. This will suggest that the PSI is a culturally valid instrument to use in the context of Nepal among community members.

3.5 Research questions

The main research question (RQ) of this study is: *To what extent is the Positive Stigma Inquiry (PSI) a culturally valid measurement tool for assessing leprosy-related stigma among community members in Nepal?* To answer the main RQ, multiple sub-RQs are formulated based on the conceptual framework. These sub-RQs are relevant to evaluate the semantic, item, operational, and measurement validity of the PSI.

The sub-RQs of this study are:

1. What are the perceptions of community members in Nepal regarding the **semantic validity** of the PSI to assess leprosy-related stigma?
    a. How can the PSI be refined to increase its semantic validity?
2. What are the perceptions of community members in Nepal regarding the **item validity** of the PSI to assess leprosy-related stigma?
    a. How can the PSI be refined to increase its item validity?
3. What are the perceptions of community members in Nepal regarding the **operational validity** of the PSI to assess leprosy-related stigma?
    a. How can the PSI be refined to increase its operational validity?
4. To what extent does the PSI have adequate **measurement validity** to assess leprosy-related stigma among community members in Nepal?
    a. How can the PSI be refined to increase its measurement validity?

4. Methodology

4.1 Research design

This study used a cross-sectional scale validation design, with a mixed-methods approach. The application of both qualitative and quantitative methods is essential in a scale validation study because this triangulation delivers more knowledge about the validity and quality of the instrument (Grand-Guillaume-Perrenoud et al., 2023). Herein, an exploratory sequential design was followed, indicating that qualitative data collection and analysis was conducted prior to quantitative data collection and analysis. Therefore, this validation study started with the qualitative assessment of semantic, item, and operational validity, to acquire an in-depth understanding of the perspectives and experiences of the respondents regarding the PSI scale and its questions (Gray, 2021). Initially, semantic validity was measured, to ensure that the PSI had the same meaning in the translated (Maithili) version. If refinement was required, the language of items was revised before testing again. Then, item and operational validity were assessed to explore whether the respondents seemed to comprehend the items and answer options. Subsequently, measurement validity was evaluated quantitatively by conducting a large number of scale interviews and testing the psychometric properties (Terwee et al., 2007). This data was beneficial for determining whether the PSI is a suitable and reliable instrument to measure health-related stigma in the context of Nepal (Souza et al., 2017).

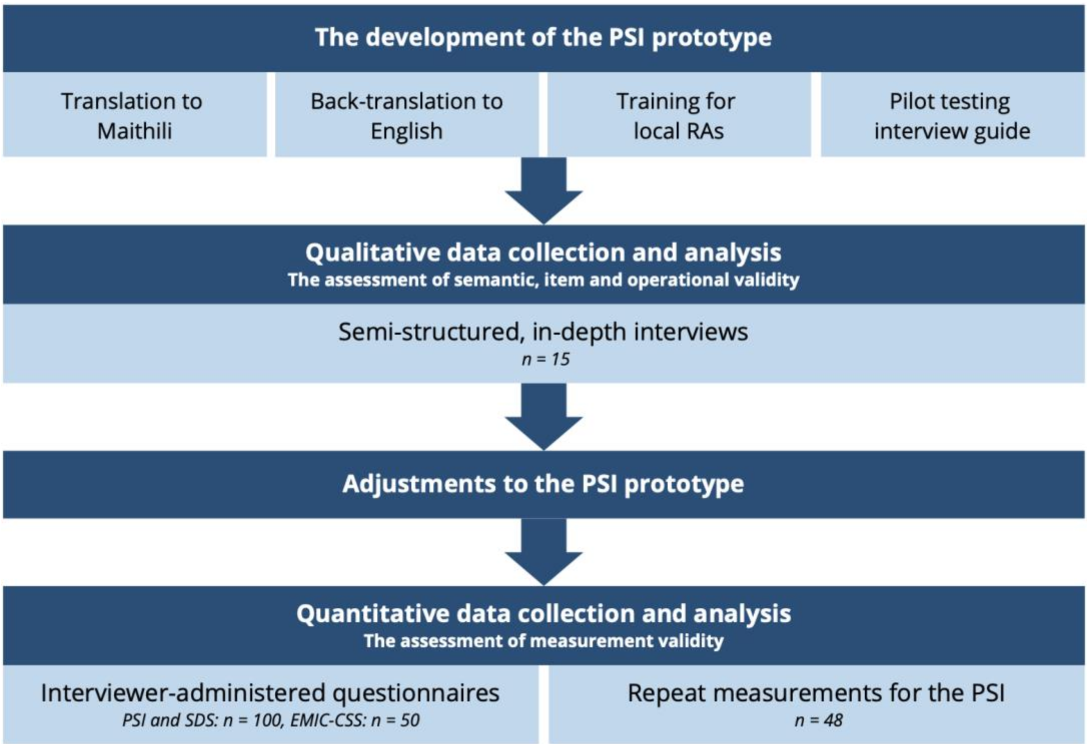
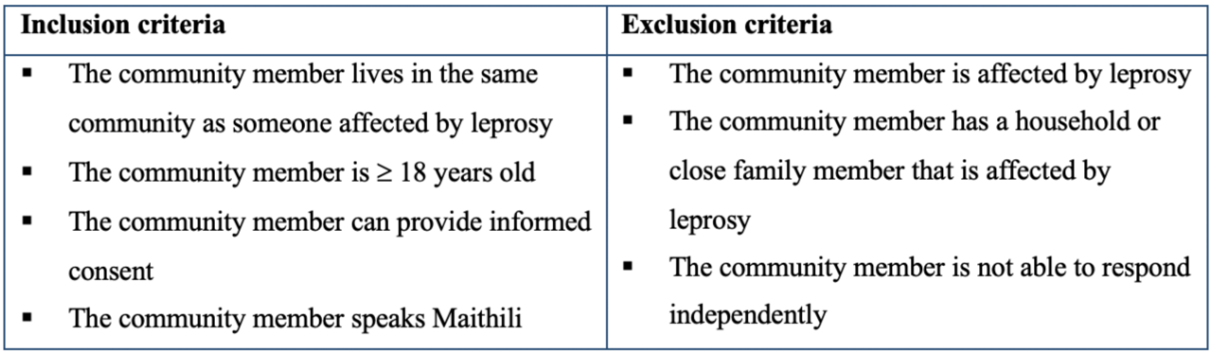


Figure 3. Methodology overview representing the exploratory sequential research design that was followed in this validation study. Qualitative data collection and analysis were performed prior to quantitative data collection and analysis. RAs in the figure refers to research assistants.

4.2 Study population and sampling

The study population was composed of local community members from villages in the Dhanusha and Sarlahi districts for the qualitative part, whereas the quantitative part included community members from the Dhanusha, Mahottari and Sarlahi districts. Fifteen in-depth interviews were conducted, because data saturation had been reached at this point. For the quantitative part, the sample size was calculated based on the number of items in the PSI. The study by Terwee et al. (2007) describes that the minimum sample size should be seven times the number of scale items. The PSI includes thirteen items for community members (this study's target group), which means that the sample size for the quantitative phase was 100. For sample selection, the inclusion and exclusion criteria were followed as described in Table 2.

Table 2. The inclusion and exclusion criteria for the sample selection for both the qualitative and quantitative components of this study.



Inclusion criteria	Exclusion criteria
▪ The community member lives in the same community as someone affected by leprosy ▪ The community member is ≥ 18 years old ▪ The community member can provide informed consent ▪ The community member speaks Maithili	▪ The community member is affected by leprosy ▪ The community member has a household or close family member that is affected by leprosy ▪ The community member is not able to respond independently

For the qualitative and quantitative components of this study, variation and convenience sampling techniques were used to select participants. Variation sampling aims to analyse the study's issue from as different perspectives as possible (Suri, 2011). It was important that community members with varying levels of stigma towards leprosy were included, to ensure that the findings were representative for those with high and those with low levels of stigma. Therefore, participants were selected from various areas in the districts, communities, gender, and age. Convenience sampling is also a non-probability strategy and was employed to select participants in the sample who were most convenient to approach, mainly because of availability or willingness to engage in this study. Therefore, community members from villages in the Dhanusha, Mahottari, and Sarlahi districts were asked to participate in interviews or in questionnaires until the sample size or data saturation was reached (Nikolopoulou, 2023).

4.3 Data collection

Prior to the data collection process, the PSI questionnaire was translated from English to Maithili, also known as forward translation, by a bilingual interpreter who is familiar with leprosy and stigma. This was critical in ensuring that the translated version of the PSI matched the original scale. For the forward translation, it was essential to use language that would be understood by persons from different educational backgrounds, e.g., community members who are low literate. The PSI was then back-translated from Maithili to English by a student in Kathmandu, who had little understanding of the PSI's content to prevent them guessing what the meaning of a given term or question may have been. The back-translation procedure was crucial to guarantee accuracy of the translation by allowing us to check that not only the words but also the meaning of the translated questions was similar to the original scale (Tsang et al., 2017). The study's researchers and the principal investigator (PI) subsequently compared the primary (English) PSI version to the back-translated version. Consequently, minor alterations have been made to the PSI in Maithili, as shown in the table in Appendix X.

4.3.1 Qualitative data collection

Qualitative data about the community's perceptions on the PSI was gathered through in-depth, semi-structured interviews using an interview guide (Appendix IV). The semi-structured format contributed to obtaining more specific answers by asking the respondent for clarifications on their statements, which is called probing (Gray, 2021). As most local community members do not speak English, local research assistants (who were also the interpreters) were trained in how to probe, build rapport, and conduct the interviews for this study. Then, the interview guide was piloted with a small sample to evaluate whether these participants understood the questions in the interview guide. The pilot testing was performed on two participants who were not included in the data collection phase of this study. The research assistants obtained the interviewee's informed consent and socio-demographic information prior to the interview (Appendixes II.I and III). The interview guide focused on semantic, operational, and item validity of the PSI. This included questions regarding the relevance and acceptability of the PSI items and the meaning of items to guarantee uniformity across different language versions (English and Maithili) of the PSI. Moreover, interviewees gave feedback related to their understanding of item phrases and response scale categories. During the qualitative data collection process, adjustments to the PSI were made in order to achieve semantic, item, and operational validity. All interviews took approximately 30-45 minutes and were audio-recorded with the permission of the participants.

4.3.2 Quantitative data collection

Following the qualitative part, quantitative data was obtained through interviewer-administered questionnaires to assess the measurement validity of the PSI. The PSI was interviewer-administered using a structured interview guide in the local language (Appendix V.V). Prior to the quantitative data collection process, local research assistants were trained on how to conduct the PSI questionnaire on community members. Then, the research assistants obtained the interviewee's informed consent and socio-demographic information (Appendixes II.II and III) and subsequently started the quantitative data collection procedure. Forty-eight repeat interviews were performed on the same participants within a timeframe of seven to ten days, as recommended by Terwee et al. 2007. Furthermore, both the Maithili versions of the EMIC-CSS (*n* = 50) and SDS (*n* = 100) (Appendixes VI.II and VII.II), available from prior research at NLR, were also administered to the participants for the assessment of the psychometric property's *criterion* and *construct validity*. This was critical for determining whether the PSI scores differ from the EMIC-CSS/SDS scores (see *quantitative data analysis* in Chapter 4.4.2). The questionnaires were administered in the following order: (1) SDS, (2) PSI, (3) EMIC-CSS. All interviewer-administered questionnaires took approximately 30-45 minutes.

Table 3. The data collection instruments used in this study were the PSI, EMIC-CSS and SDS. This table provides a general overview of these health-related stigma scales.

PSI	▪ Consists of thirteen scale items ▪ Response scale is a Likert scale: (5) = all the time – (0) = I don't know ▪ High scores indicate high levels of stigma among respondents
EMIC-CSS	▪ Consists of fifteen scale items ▪ Response scale is a Likert scale: (2) = yes – (0) = don't know ▪ High scores indicate high levels of stigma among respondents
SDS	▪ Consists of a vignette and seven scale items ▪ Response scale is a Likert scale: (0) = definitely willing – (3) = definitely not willing ▪ High scores indicate high levels of stigma among respondents

4.4 Data analysis

4.4.1 Qualitative data analysis

The research assistants transcribed the in-depth interviews verbatim in local language and subsequently translated the transcripts into English. Then, the transcripts were coded with the program ATLAS.ti, to recognise patterns within the data through thematic analysis (Braun & Clarke, 2006). Coding was employed using a combination of deductive and inductive approaches. Beforehand, a code book was created that covered the main themes from this study's conceptual framework and was updated throughout the course of data analysis if new codes emerged from the data (Appendix IX). The deductive approach was used to explore the cultural validity domains of this study's conceptual framework, such as whether the community members understood the questions in the translated (Maithili) version of the PSI. The inductive approach was used for examining unexpected findings related to the perspectives of the interviewees on the PSI and its items. The codes of these unexpected outcomes were added to the code book. Then, the codes were grouped into main themes *(semantic, item, and operational validity)* that were most relevant for answering the RQ of this study (Braun & Clarke, 2006; Gray, 2021). Besides this, the inductive approach provided no new analytical themes.

4.4.2 Quantitative data analysis

Quantitative data from the questionnaires were anonymously entered in the software KoboToolbox and analysed with IBM SPSS Statistics 27. Questionnaires with > 10% missing values were omitted from the analysis. If questionnaires had ≤ 10% missing values, items with missing data were substituted by the median score of all answers to the same questions. To assess measurement validity of the PSI, the following six psychometric properties were quantitatively analysed: *internal consistency, criterion validity, construct validity, reproducibility, floor and ceiling effects, and interpretability*. The quality criteria provided by Terwee et al. (2007) were used for measuring these psychometric properties:

- *Internal consistency* of the PSI was calculated with the Cronbach's alpha, which should be between 0.70 – 0.95.
- *Criterion validity* was measured using the Spearman's rank correlation test. The correlation with the gold standard (the EMIC-CSS and SDS for this study) should be ≥ 0.70. *Construct validity* was tested by the validation of predefined hypotheses. Herein, the PSI scores were correlated with the EMIC-CSS and SDS scores and was positive rated if 75% of the predetermined hypotheses were confirmed. In this study, the predefined hypothesis was that there would be a positive, significant, but not very strong, correlation between the PSI and EMIC-CSS/SDS scores. This correlation was also measured with the Spearman's rank correlation test. For *criteria* and *construct validity*, the Spearman's rank correlation test was suitable for both normal and non-normal distribution of data.
- *Agreement* was assessed with the smallest detectable change (SDC).
- *Reliability* was measured with the intraclass correlation coefficients (ICC) or weighted Kappa and should be ≥ 0.70 for good reliability of the PSI.
- *Floor and ceiling effects* occurred when ≥ 15% of the respondents reached the lowest or highest possible scores on the PSI.
- The *interpretability* of the PSI was assessed by measuring the median and interquartile ranges (IQR) of the sum scores (because of non-normally distributed scores) for the following subgroups: sex, age of participants, education, and employment status.

4.5 Quality control

Quality control methods were critical for this study since data was collected by local research assistants with minimal experience in conducting research methods. Prior to data collection, the local research assistants were introduced to the study and given a training of two days in conducting semi-structured interviews and interviewer-administered questionnaires. To identify and improve mistakes at an early stage, the study's researchers observed the local research assistants during the data collection phase. Regular meetings were organised with the local research assistants to discuss the findings, adjust the interview guide if needed, and to re-train them if necessary.

Validity refers to how accurate the study evaluates or represents the concepts that are being studied (Noble & Heale, 2019). Hence, pilot testing of the interview guide was crucial to increase the validity of the study. The pilot testing aimed to identify and correct any weaknesses in the interview guide before applying the interviews to the study population (Srinivasan et al., 2017). Triangulation of research methods, a representative study sample, and extensive trainings for local research assistants also increases the validity of the study. Using triangulation of research methods (both qualitative and quantitative) in a study provides multiple datasets to clarify different elements of the study's issue, which reinforces the results (Noble & Heale, 2019). The study sample is considered representative if the study's results are generalisable to the target population (Rudolph et al., 2023). For this validation study, community members with high and low levels of stigma were included to ensure that the PSI is applicable to people with varying stigma levels. Additionally, extensive training for local research assistants may increase the accuracy and consistency of data collection across participants, which reduces errors and discrepancies within the data. This enhances the validity as well as the reliability of the study.

Reliability is defined as the consistency and reproducibility of the research methods employed in the study (Bruton et al., 2000). To increase the reliability of this study, a question-by-question (QbyQ) guide was developed for the PSI and EMIC-CSS questionnaires. This guide offered standardised prompts and examples to ask when the respondent did not comprehend a question in the PSI or EMIC-CSS questionnaires, rather than the local research assistant providing his/her own questions or examples. Using the guide along with extensive training for local research assistants leads to clear and standardised data collection procedures, which subsequently increase the reliability of the study (Johnson & Turner, 2003).

4.6 Ethical considerations

Ethical approval for this validation study was obtained by the Nepal Health Research Council (NHRC) on May 10th, 2024 (Appendix XI). Community members were asked to give informed consent prior to participating in the interviews or questionnaires. The consent form was translated into local language (Maithili) and subsequently explained to community members by local research assistants. Participants provided informed consent through a written signature or a fingerprint (if the participant was not able to provide a written signature) on the consent form. No incentives were provided to the community members for participating in this study. Moreover, all data, including transcripts, were stored on a secure platform managed by NLR to ensure confidentiality and were only accessible to the study's researchers and project team members.

5. Results

The results section presents the socio-demographic information from community members who participated in the interviews and questionnaires. The qualitative section covers the findings related to semantic, item, and operational validity of the PSI. Subsequently, findings related to the measurement validity of the PSI will be presented, including quantitative assessments of internal consistency, criterion validity, construct validity, reproducibility, floor and ceiling effects and interpretability.

5.1 Qualitative results

5.1.1 Socio-demographics of participants from the semi-structured interviews

Fifteen participants have been interviewed for the qualitative part of this study and their socio-demographic information are indicated in Table 4. The study sample consisted of more females (53%) than males. The participants' ages ranged from 24 to 70 years old, with a mean of 37,7 and a median of 36,0 years. A large group of the study sample did not receive any schooling. Most participants were employed, currently married and everyone lived with their family in villages. In total, two participants were excluded from the study; one had no leprosy-affected people in his community, and one was not able to understand the questions from the interview.

Table 4. Socio-demographic information of the participants from the semi-structured interviews.

Participant code	Village	Age	Sex	Religion	Education	Employment status	Marital status	Living situation
CM01	Laxminiya	50	Female	Hinduism	No schooling	Unemployed	Currently married	With family in village
CM02	Barhampuri	26	Female	Hinduism	No schooling	Unemployed	Currently married	With family in village
CM03	Barhampuri	70	Male	Hinduism	No schooling	Unemployed	Widow	With family in village
CM04	Tribhuwan Nagar	36	Male	Hinduism	Primary school	Unemployed	Currently married	With family in village
CM05	Tribhuwan Nagar	24	Male	Islam	Bachelors	Computer operator	Currently married	With family in village
CM08	Sarhansiya	47	Female	Hinduism	No schooling	Farmer	Currently married	With family in village
CM09	Kamat	25	Female	Hinduism	No schooling	Farmer	Currently married	With family in village
CM10	Jhojhi Kataiya	42	Male	Hinduism	High school	Ambulance driver	Currently married	With family in village
CM11	Lakhauri	40	Female	Hinduism	No schooling	Female health volunteer	Currently married	With family in village

CM12	Phulgamma	34	Female	Hinduism	No schooling	Sweeper at a health post	Currently married	With family in village
CM13	Phulgamma	27	Male	Hinduism	Bachelors	Shop owner	Currently married	With family in village
CM14	Raghapur	30	Male	Hinduism	Bachelors	Teacher	Currently married	With family in village
CM15	Sitanagar	24	Female	Hinduism	Bachelors	Human Resources	Single / Never married	With family in village
CM16	Sarajawak	43	Male	Hinduism	Primary school	Barber	Currently married	With family in village
CM17	Bhagwan-pur	47	Female	Hinduism	Middle school	Guesthouse owner	Currently married	With family in village

CM = community member

5.1.2 Assessment of semantic validity

Semantic validity assesses whether the meaning of the translated (Maithili) PSI items was well understood and clear to the community members. Therefore, the following questions were asked for each item in the PSI to assess sematic validity: *(1) Did you find the question easy to understand? (2) Can you repeat the question in your own words? (3) Were any words in the question unclear to you?* An overview of the respondents' answers regarding each item in the PSI are presented in Table 5.

The majority of the participants found all PSI items easy to comprehend, as evidenced by their ability to explain their responses to the PSI items. Participants with higher education levels, in particular, were able to explain their responses to all questions in the PSI. Amongst the respondents who are low literate, one was unable to give any explanations at all, whereas the others were able to explain their responses to some items. For example, community members explained their responses to Items 6 *('Would people in your community respect the family of a person with leprosy?')* and 11 *('Would an employer be willing to hire a person with leprosy?')* as follows:

> *"As I said earlier, things were different in the past. But things have changed now. People are aware and educated and they understand things. In the past, people were disgusted with the patient and their family as well. Now they are not." (CM10, male) – Item 6.*

> *"If one has leprosy, then how can anyone hire them? One can't work with leprosy. If they can't work, why would anyone hire them?" (CM08, female) – Item 11.*

Two participants mentioned not understanding Item 3 *('After finding out that a person has leprosy, would a community member have the same (or more) respect towards this person?')* in the PSI. No further data was obtained to explain why these participants did not easily understand this item. However, both participants were able to respond to the item, with one even providing an explanation.

> *"He has leprosy, he is poor and sad, so people will respect him even more." (CM01, female) – Item 3.*

Additionally, it was noticed that the participants, particularly the ones who were low literate, understood the items better when examples from the QbyQ guide were used (see the essence of this guide in Chapter 4.5). This led to participants being able to provide responses with explanations to the PSI items. For instance, one participant did not initially understand Item 6 *('Would people in your community respect the family of a person with leprosy?')* but was able to respond when an example from the QbyQ guide was provided.

> *"They would. If they have leprosy in the family, they would obviously respect the person." (CM11, female) – Item 6.*

Therefore, it was decided to integrate one example from the QbyQ guide to each item in the PSI. These were subsequently tested among six participants. The use of examples made the PSI items easier for respondents to understand. Furthermore, it turned out that Items 7, 8, and 10 were challenging for participants to distinguish whether the question concerned the family members of the person affected by leprosy or the person affected themselves. Including examples for each item also helped to clarify this. The following statement demonstrates a respondent's answer to Item 10 *('Would a community member be willing to marry a relative of a person with leprosy?')* prior to the insertion of an example:

> *"Uhm, yes. They would be willing to marry a person with leprosy but as you can see in our community, people consider leprosy as a communicable disease. So, chances are high that they won't marry." (CM05, male) – Item 10.*

Item 8 was described as: *'Would the family member of a person with leprosy feel comfortable talking about it to their friends?'.* One participant referred in his answer to the person with leprosy (instead of the family members) talking to their friends. Even after an example was added to this item, one participant mentioned in her response that people suffering from any kind of disease should talk about it to their friends. This indicates that Item 8 was still unclear. For that reason, this item was rewritten to: *'Would a family member feel comfortable telling others that someone in the family has leprosy?'* and tested among the final three participants. The revised item resulted in a greater comprehension among all three respondents. The following quote demonstrates a respondent's answer to the revised item:

> *"Because, okay talking about my family, for example someone from my family like mom, dad, or brother. If anyone of them has leprosy, then I, myself, would not share about it to you or anyone else. It is possible that you will break the friendship with me when you get to know that I have leprosy in my house." (CM15, female) – (revised) Item 8*

The participants were also asked to repeat the items in their own words, to determine whether the questions in Maithili are comparable to the English version and if the items are indeed well understood. Not all participants were able to paraphrase the items in their own words, particularly the ones who were low literate. This may be due to the difficulty of the question, or because the participants did not understand how to respond, which led to some insecurities and frustrations amongst them.

> *"We don't go anywhere out. We just live in our house all day long. I don't know anything. I am uneducated." (CM02, female).*

However, the participants who were highly literate also faced challenges in paraphrasing several items from the PSI in their own words. Occasionally, they responded directly to the item rather than paraphrasing the question in their own language. These paraphrases were categorised as *'unable'* in the overview in Table 5. For instance, one participant rephrased Item 1 *('Would a person with leprosy be willing to tell others about their condition?')* as follows:

> *"Uhm, a person with leprosy, uhm, would not want to share about their condition out of shame. Also, because the village and community treat them bad. Nobody would go near the person or his/her house as well." (CM14, male) – Item 1.*

Therefore, it was decided to ask participants who were experiencing difficulties in answering the repeat question to provide examples related to the items. However, the respondents did not want to do this or found it difficult to provide examples. One participant considered the repeat question unnecessary and declined to answer because the paraphrases would be similar to the items. Two respondents were able to paraphrase some items, while four participants successfully paraphrased almost all items in their own words. The following quotes demonstrate successful paraphrases for Items 4 *('Would other people in your community be willing to interact with a person affected by leprosy?')* and 5 *('Would people be willing to visit the home of a person affected by leprosy?')*:

> *"Uhm, it means if the community members want to talk to the person with leprosy or not." (CM05, male) – Item 4.*

"It says that whether someone will go to the person with leprosy's home to drink tea or eat food." (CM16, male) – Item 5.

We observed that Item 2 was not correctly paraphrased by four participants. Item 2 states: *'Would a community member feel comfortable living near a person with leprosy?'*. No one mentioned *'living near'* or a synonym for this term in their paraphrases. Instead, the respondents used the terms *'be around'*, *'sit with'*, *'go near'*, or *'gather around'*, even with the example used from the QbyQ guide saying: *'someone is not scared to live next to a person with leprosy'*. Apparently, the term *'living near'* in Maithili has multiple definitions, such as *'being around'*. However, the translation for *'living near'* in Maithili used in the PSI seemed to be the most suitable and there was no better alternative. Therefore, it was decided to change the example for Item 2, to prevent confusion and to make it clear to the participants that the question is about living near someone with leprosy. The modified example states: *'Would someone feel comfortable being a neighbour of a person with leprosy?'*.

No participant mentioned any unclear words in the PSI items. However, to determine whether the respondents indeed understood the potential difficult words in the items, such as *'feeling comfortable'*, or *'to interact'*, we asked for examples regarding these terms. This was tested among three participants, but only one was able to give examples to the terms *'feel comfortable'*, *'respect'*, *'to interact'*, *'to tell'*, and *'to visit'*.

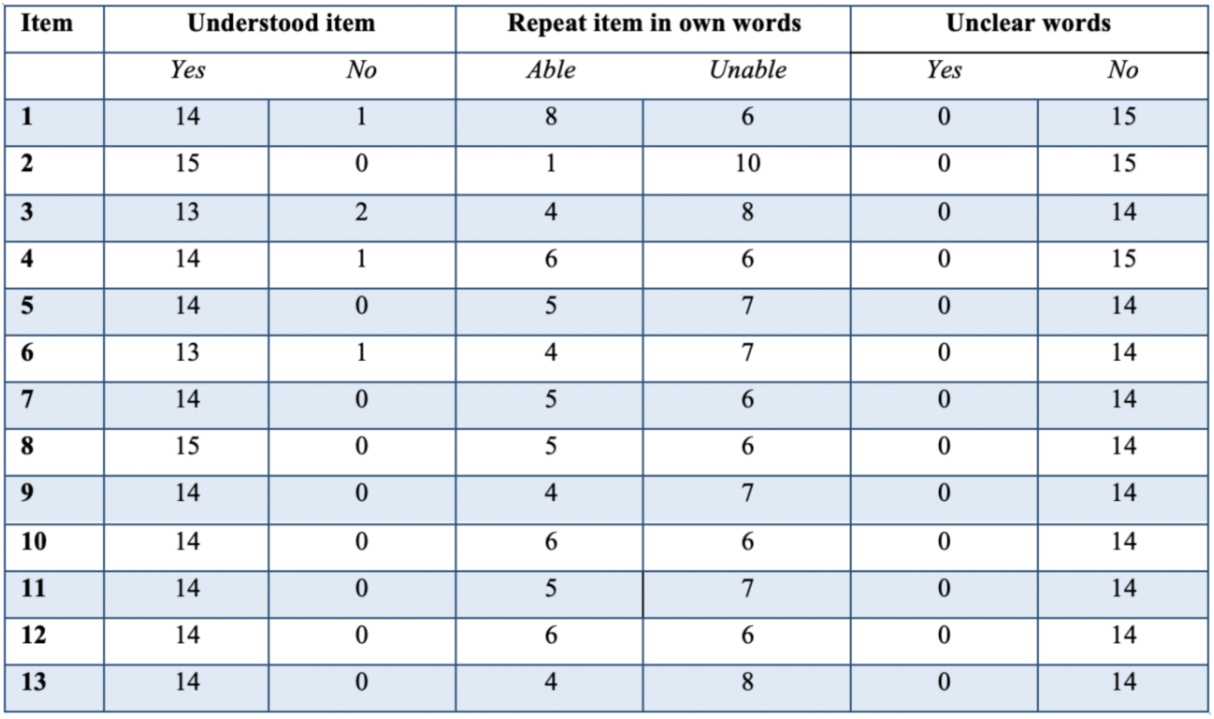
"My husband has four brothers and one of them doesn't want to look after my in-laws. He says: "my parents didn't spend money on me, so I don't care about them". But, in my point of view, no matter whether the parents gave you or not, you can never pay the debt of bringing you in this world. Your mom carried you for nine whole months." (CM12, female) – Example for the term 'respect'.

The other two participants were generally struggling, or it was too difficult for them to provide any examples. Hence, the final three participants were asked to clarify the meaning of certain terms. This was considered somewhat easier, and the three respondents described the meanings or provided examples for:

- **Comfortable:**
  "It means that if someone will feel easy." (CM15, female)
- **Respect:**
  "Respect means considering highly of." (CM16, male)
  "It means to look up to." (CM17, female)
- **To interact:**
  "Just like we are talking right now." (CM15, female)
  "To interact means just like we are talking right now." (CM16, male)

- **Be accepted:**
  "Like, for example, if we are friends and we used to visit each other's home. Are we still allowed to go like we used to go before?" (CM15, female)

Table 5. Overview of the participants' responses concerning the comprehension of the PSI items, how the items were paraphrased in their own words, and if there were any unclear words in each item.



Item	**Understood item**		**Repeat item in own words**		**Unclear words**	
	Yes	*No*	*Able*	*Unable*	*Yes*	*No*
1	14	1	8	6	0	15
2	15	0	1	10	0	15
3	13	2	4	8	0	14
4	14	1	6	6	0	15
5	14	0	5	7	0	14
6	13	1	4	7	0	14
7	14	0	5	6	0	14
8	15	0	5	6	0	14
9	14	0	4	7	0	14
10	14	0	6	6	0	14
11	14	0	5	7	0	14
12	14	0	6	6	0	14
13	14	0	4	8	0	14

5.1.3 Assessment of item validity

To assess item validity, two questions were asked during the interviews concerning the relevancy and acceptability of each item in the PSI: *(1) Is this question relevant for you and other community members? (2) Would you feel comfortable with answering this question if you had to?* Most participants found almost all items relevant (see Table 6). For example, the respondents explained their answers to the relevancy of Items 3 *('After finding out that a person has leprosy, would a community member have the same (or more) respect towards this person?')* and 13 *('How often is the person's own name used instead of the name 'leprosy patient' when people talk about him/her?')* as follows:

"Because we should not treat them bad, it will hurt them. If we maintain distance from them, they will feel really bad about their life that everyone is disgusted by him/her. The person feels so underestimated. (CM14, male) – Item 3.

"Because they are human too. It is not good to call them by their disease instead of their own names." (CM12, female) – Item 13.

One participant mentioned that Items 3, 4, and 8 to 13 were irrelevant to him and other community members. However, based on the responses it was observed that the respondent did not fully understand the question concerning the relevance of the items. His explanations for why an item was considered irrelevant were vague or related to what people should do. For instance, when asked about the relevance of Item 12 *('Would people be willing to buy food from a person affected by leprosy?')*, his response was that people should buy it. Items 11 *('Would an employer be willing to hire a person with leprosy?')* and 12 (see question above) were also considered as irrelevant for the community by another respondent. He explained that an employer would not want to hire someone with leprosy because he would risk losing other employees (irrelevancy of Item 11), and that people in his community generally will not buy any food from people affected by leprosy (irrelevancy of Item 12).

Another participant mentioned that the PSI in its entirety is *'kind of'* relevant for herself and other community members. Her explanation was that the questionnaire is appropriate for educated people, implying that it might be irrelevant for people who had received no schooling. The other respondents considered the questionnaire in its entirety as relevant.

> *"I think it is because all the people, even from outside, are willing to improve the condition of our communities. The feeling of discrimination and disgust should be eradicated. Everyone should work hard to reduce the possibilities of diseases or illness by being responsible." (CM04, male) – Relevancy of the questionnaire in general.*

Furthermore, one participant said feeling *'kind of'* comfortable to answer Items 5, 8, and 11 (not indicated in Table 6). This answer may imply uncertainty. No additional explanation was obtained on why this respondent did/did not feel comfortable answering these three questions. Apart from this participant, everyone else felt comfortable answering the PSI items. The statement below demonstrates a participant's response to feeling comfortable answering Item 4 *('Would other people in your community be willing to interact with a person affected by leprosy?')*:

> *"I am not even a bit hesitant to reply to your questions because I feel so comfortable, because these questions are very related to our lives. We all have seen or experienced this before in our communities." (CM15, female) – Item 4.*

Every respondent stated that they felt comfortable during the interview process. However, one participant did not feel completely comfortable, as she was concerned for the recording being leaked to the leprosy patients in her community. She felt more at ease after being reassured that the audio will be deleted once the transcription was finished.

"No, you assured me that nothing is going to happen to me. Nobody would say anything to me. You will study abroad about it and make reports. So, I am not afraid anymore." (CM11, female).

Table 6. Overview of the participants' responses concerning the relevancy and acceptability of the PSI items.

Items	**Item relevance**		**Item acceptability**	
	Yes	*No*	*Yes*	*No*
1	13	1	15	0
2	15	0	15	0
3	13	1	14	0
4	13	1	14	0
5	12	1	14	0
6	13	0	14	0
7	13	0	13	0
8	13	1	13	0
9	12	2	13	0
10	12	2	14	0
11	12	2	13	0
12	12	2	14	0
13	13	1	14	0

5.1.4 Assessment of operational validity

Table 7 demonstrates the questions that were asked to the participants to assess operational validity. The majority of the participants understood the different answer options, said that the answer options match the items, and understood the instructions of the PSI. The interviewer-administration mode was suitable for the community members since most respondents were low literate. Additionally, the local language (Maithili) has several dialects and the interviewer-administered method ensured that community members from different districts were able to understand the PSI items.

Table 7. Overview of the participants' opinions regarding the instructions and response scale of the PSI.

Questions	**Yes**	**No**
Understood the answer options?	13	1
Answer options suit the items?	13	0
Understood the instructions?	12	1

5.1.5 Adjustments to the Positive Stigma Inquiry

Adjustments were made to the PSI based on the qualitative findings. In addition, various examples used from the QbyQ guide did not match the flow of the response scale or the purpose of the PSI, which is the use of neutral or positive formulations. Based on the discussion with the research team, alterations were made to these examples. Table 8 summarizes the adjustments described in the subsection *'assessment of semantic validity'*, as well as the adapted examples. The final version of the PSI is included in Appendix V.II.

Table 8. Adjustments that were made to the PSI questionnaire during the qualitative data collection and analysis phase.

Item/example for item #	**First version of the item/example**	**Final version of the item/example**	**Explanation for the changes**
Item 8	Would the family member of a person with leprosy feel comfortable talking about it to their friends?	Would a family member feel comfortable telling others that someone in the family has leprosy?	It seemed to be unclear for the participants whether the question concerns the family members or the person with leprosy. Therefore, this item was revised so the respondents understand that the question is about family members.
Example for item 2	For example, someone is not scared to live next to a person with leprosy.	For example, would someone feel comfortable being a neighbour of a person with leprosy?	The first version of the example does not match the flow of the response scale. Another reason for modifying this example was because the paraphrases for Item 2 did not include *'living near'* or a synonym, and there was no better alternative for this term in Maithili.
Example for item 6	For example, people in the community support the family of a person with leprosy.	For example, would people in the community ask for the opinion of the family of a person with leprosy?	*'Support'* was considered not an ideal example that suits the concept *'showing respect'* stated in Item 6.
Example for item 7	For example, people in the community engage with the family of a person with leprosy.	For example, would people in the community invite the family of a person with leprosy to community events?	The term *'engage'* was too abstract.
Example for item 9	For example, someone wants to marry a person	Deleted.	This example was deleted since Item 9 was

	after finding out that he/she has leprosy.		obvious and well understood by the respondents. So, there was no need for an example.
Example for item 13	For example, I heard there lives a leper in the neighbourhood.	For example, saying *‘kustharogi’* instead of Mr. Singh?	The term ‘*leper’* is negatively loaded and so should not be used in the PSI. For that reason, the example was changed to a more neutral formulation including *‘kustharogi’*, which means *‘leprosy patient’*.

5.2 Quantitative results

5.2.1 Socio-demographics of participants from the questionnaires

The quantitative part of this study included 100 participants, whose socio-demographic characteristics are presented in Table 9. More females participated in the quantitative study (60%) than males, and the majority of the participants did not receive any schooling. The 18% of ‘other’ responses on education level indicate a bachelor’s, master’s, or literacy classes. Additionally, a large group of the study sample was employed. Herein, the 55% ‘other’ responses from participants imply employment such as a teacher, tailor, salesman, pharmacist, social worker, health assistant, or in the farming. Most participants were married and lived with their family in villages.

Table 9. Socio-demographic information of the participants from the interviewer-administered questionnaires.

	Participants (N)	Percentage (%)
Age		
≤ 24 years	16	16
25 – 44 years	68	68
45 – 64 years	15	15
≥ 65 years	1	1
Mean age (SD)	33.69 (10.18)	
Sex		
Male	40	40
Female	60	60
Religion		
Hinduism	94	94
Islam	5	5
Christianity	1	1
Education		
No schooling	33	33
Primary school	10	10
Middle school	15	15

High school	7	7
Higher secondary	15	15
Other	20	20
Employment status		
Unemployed	33	33
Self-employed	1	1
Service-holder	5	5
Labour work	4	4
Student	2	2
Other	55	55
Marital status		
Currently married	87	87
Widow(er)	4	4
Divorced	1	1
Single / never married	8	8
Living situation		
With family in village	95	95
Alone in village	5	5

SD = standard deviation

5.2.2 Score characteristics of health-related stigma scales

First of all, during the quantitative data collection phase it was observed that Item 13 *('How often is the name of 'leprosy patient' used instead of the person's own name when people talk about him/her?')* did not match the response scale. This was corrected by modifying Item 13 into: *'How often is the person's own name used instead of the name 'leprosy patient' when people talk about him/her?'* and was immediately implemented for the remaining interviews. Responses to the previous item were reverse coded for the quantitative analysis.

Table 10 provides the median, minimum (min.), and maximum (max.) sum scores of health-related stigma scales used in this study. The median sum score in the PSI was 35.5, with a minimum of 13.0 and a maximum of 61.0. A total of thirteen missing values were identified across nine different items in the PSI. Concerning the SDS scale, the median of the total scores was 3.0. The minimum and maximum scores were 0.0 and 15.0. Seven missing values were observed in the SDS, divided over three distinct items. The median of the EMIC-CSS's sum scores was 20.0, with a minimum and maximum score of 1.0 and 30.0. In the EMIC-CSS, a total of five missing values were found across four different items. None of the PSI, SDS, and EMIC-CSS questionnaires had > 10% missing values and therefore, none were omitted from the analysis. The missing values were substituted by the median score of all responses to the same items. Figures 4A/B/C demonstrate the percentage of the scores for each item in the PSI, EMIC-CSS, and SDS scales.

Table 10. Characteristics of the total scores from the PSI, SDS, and EMIC-CSS scales.

PSI			SDS			EMIC-CSS		
Median	*Min.*	*Max.*	*Median*	*Min.*	*Max.*	*Median*	*Min.*	*Max.*
35.5	13.0	61.0	3.0	0.0	15.0	20.0	1.0	30.0

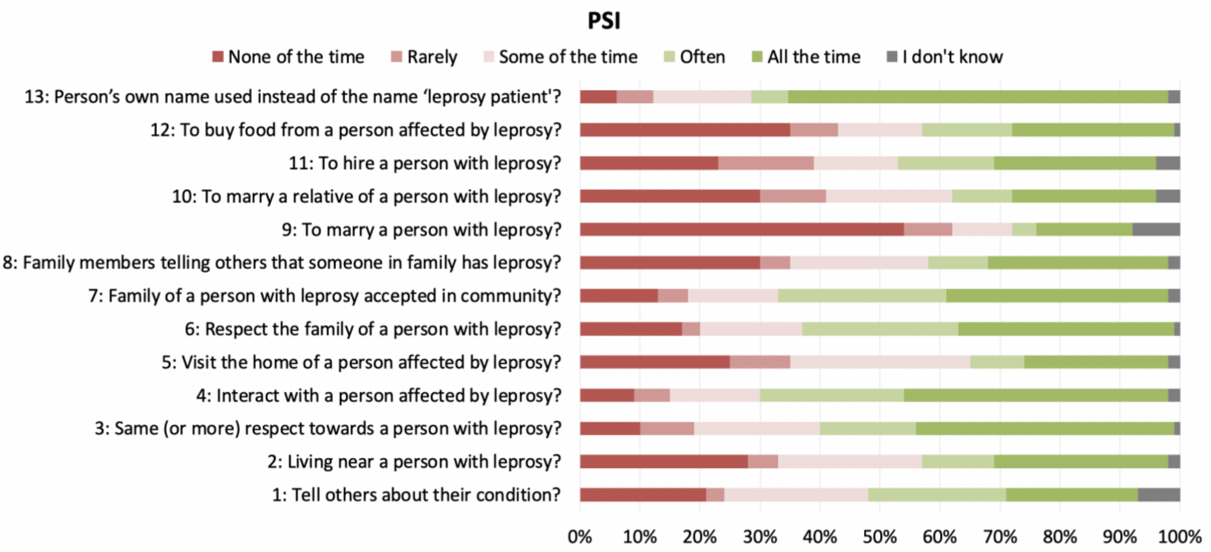


Figure 4A. Community's perceptions towards persons affected by leprosy. The bar graph demonstrates the percentage of the scores (x-axis) for each item in the PSI scale (y-axis).

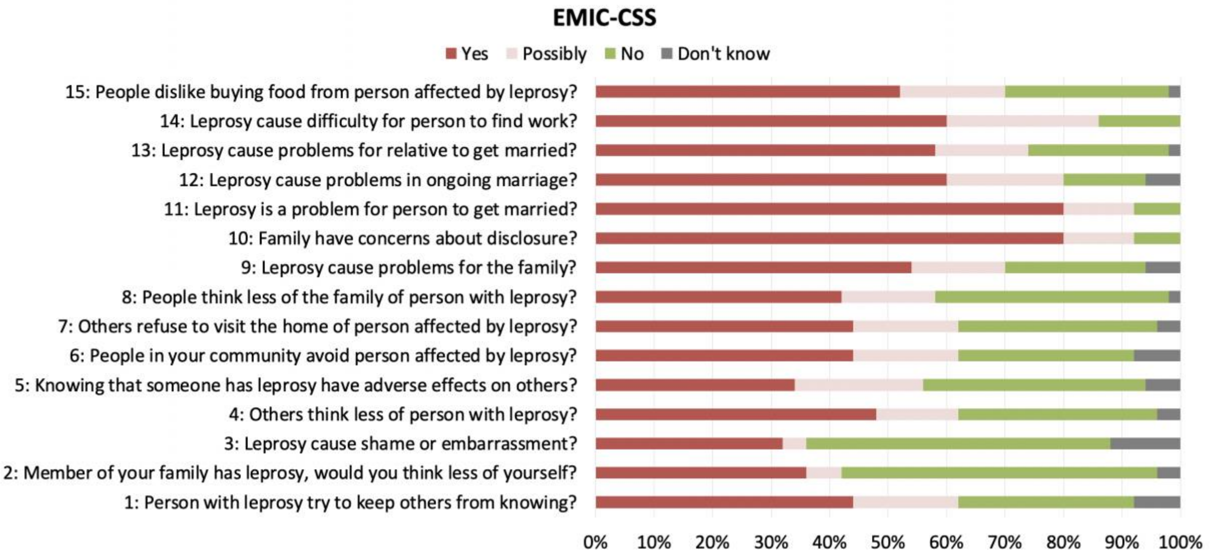


Figure 4B. Perceptions of community members towards persons affected by leprosy. The bar graph demonstrates the percentage of the scores (x-axis) for each item in the EMIC-CSS scale (y-axis).

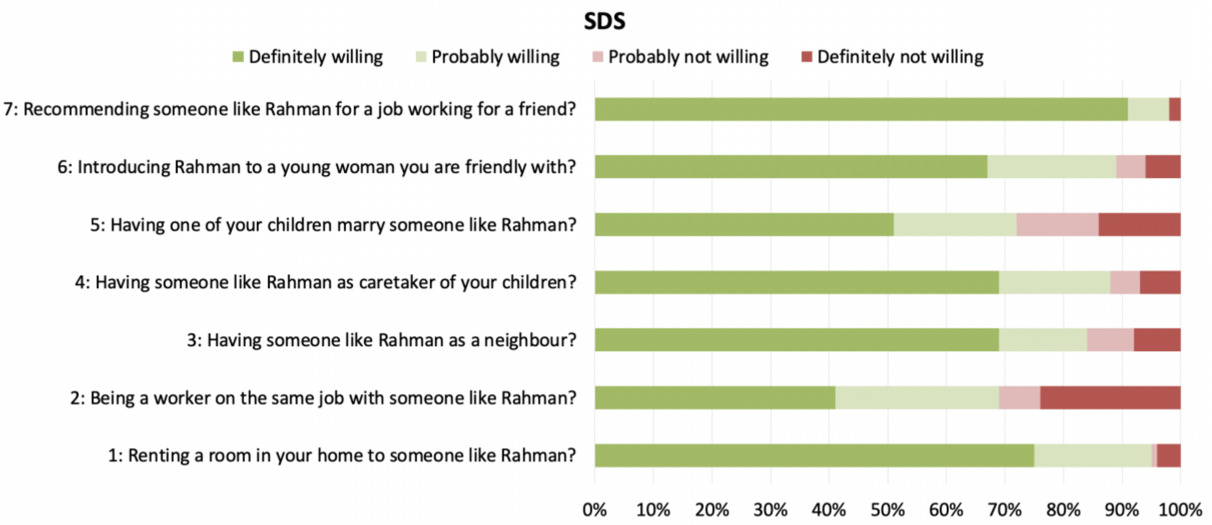


Figure 4C. Social distance desirability of community members towards a person affected by leprosy. The bar graph demonstrates the percentage of the scores (x-axis) for each item in the SDS scale (y-axis).

5.2.3 Assessment of measurement validity

Internal consistency

The Cronbach's alpha for all thirteen items in the PSI was 0.851. However, Item 13 *('How often is the person's own name used instead of the name 'leprosy patient' when people talk about him/her?')* in the PSI had the lowest item-total correlation of -0.033 (see Table 11). When Item 13 was omitted from the analysis, the Cronbach's alpha coefficient for the PSI instrument increased slightly from 0.851 to 0.869. Therefore, it was decided to remove Item 13 from the PSI, since this item has a low correlation with the PSI in its entirety. The analyses presented in the next sections were conducted excluding Item 13.

Table 11. The item – total correlation values of each item in the PSI scale.

Item	Item-total correlation
1: Tell others about their condition?	0.411
2: Living near a person with leprosy?	0.549
3: Same (or more) respect towards a person with leprosy?	0.521
4: Interact with a person affected by leprosy?	0.588
5: Visit the home of a person affected by leprosy?	0.642
6: Respect the family of a person with leprosy?	0.645
7: Family of a person with leprosy accepted in community?	0.582
8: Family members comfortable telling others that someone in family has leprosy?	0.411
9: To marry a person with leprosy?	0.573
10: To marry a relative of a person with leprosy?	0.450
11: To hire a person with leprosy?	0.635
12: To buy food from a person affected by leprosy?	0.645
13: Person's own name used instead of the name 'leprosy patient'?	-0.033

Criterion validity

The Spearman's rank correlation test demonstrated a statistically significant correlation between the total scores of the PSI and SDS; $r = 0.403$, $p < 0.05$, and although not significant, a weaker correlation was observed between the total PSI and EMIC-CSS scores; $r = 0.208$, $p = 0.073$.

Construct validity

The predetermined hypotheses suggested that there would be a positive, significant, but not very strong correlation between the total PSI and SDS/EMIC-CSS scores. However, based on the findings in *criterion validity*, the Spearman's rank correlation test showed only a statistically significant correlation between the PSI and SDS scores, indicating that < 75% of the predefined hypotheses are confirmed.

Reproducibility

In this study, repeat interviews were conducted with 48 participants. The *agreement* was assessed with the SDC. First, the standard error of the mean (SEM) was calculated as 5.33, which was then converted into SDC. The SDC in one individual (SDC_{ind}) is 14.77. However, we do not work with individuals, so the SDC in a group of people (SDC_{group}) was measured. The SDC_{group} was assessed by dividing 14.77 by the square root of 48 (n for repeat interviews). Thus, the value for SDC_{group} is 2.13.

The $ICC_{agreement}$ was used to assess the inter-interviewer *reliability* of the PSI. A two-way random effects model was employed. This model compares the total PSI scores from the first to the second (repeat) interview, in which the $ICC_{agreement}$ of the PSI resulted in 0.77. Terwee et al. (2007) defined that the $ICC_{agreement}$ should be ≥ 0.70, indicating that the PSI with an ICC value of 0.77 can be considered as a reliable measurement tool.

Floor and ceiling effects

Figure 5 demonstrates a histogram of the frequency of the total PSI scores. The Shapiro-Wilk test resulted in a p-value of 0.045, indicating that the sum scores in the PSI were not normally distributed. The histogram shows that no participants reached the lowest (0) or highest (65) possible PSI scores. This indicates that no floor and ceiling effects exist amongst the PSI sum scores of the respondents.

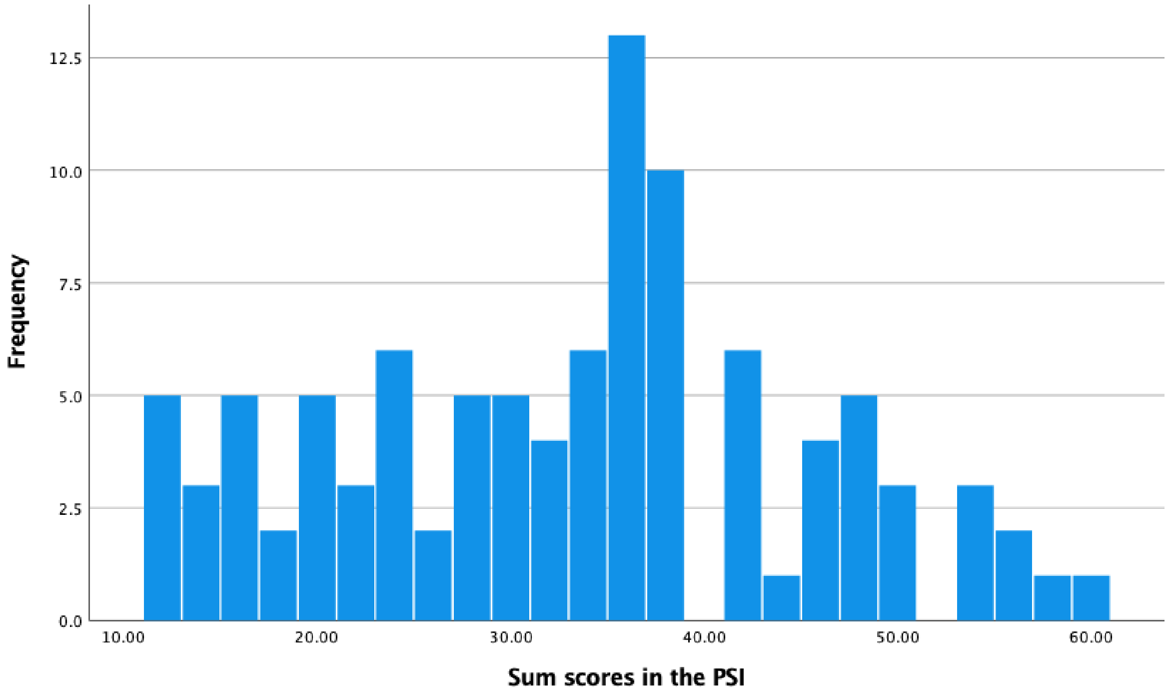


Figure 5. A histogram showing the frequencies (y-axis) of the sum scores in the PSI (x-axis). The PSI's sum scores were not normally distributed given that the Shapiro-Wilk test provided a *p*-value of 0.045 (*p*-value < 0.05 means the data is not normally distributed).

Interpretability

Different subgroups were created to assess the interpretability of the PSI (see Table 12). A higher score indicates a more negative perception of leprosy, or a person affected by leprosy. Because the PSI scores were not normally distributed, the median scores and IQRs were measured for each subgroup. In our study, the males scored significantly higher (median of 36.0; $p = 0.021$) than females (median of 30.0) on the PSI. No statistically significant differences were found among participants from different age groups, education levels, and employment status.

Table 12. The median and interquartile ranges of the PSI sum scores (with significance testing) for the subgroups *sex, age of participants, education, and employment status.*

Subgroups		**N**	**Median**	**IQR 25 – 75**	***p*-value ^{b}**
Sex	Male	40	36.0	29.5 – 45.0	0.021
	Female	60	30.0	20.0 – 37.0	
Age of participants	≤ 24 years	16	37.0	30.3 – 42.8	0.535
	25 – 44 years	68	33.0	22.3 – 41.8	
	45 – 64 years	15	27.0	23.0 – 37.0	
	≥ 65 years	1	35.0	-	
Education ^{a}	Low literate	58	30.0	20.0 – 38.3	0.064

	High literate	42	36.0	29.0 – 42.0	
Employment status [c]	Unemployed	33	36.0	26.0 – 42.0	0.178
	Employed	65	32.0	22.5– 37.0	

[a] *Low literate: no schooling, primary school, middle school, and literacy classes; High literate: High school, higher secondary, and other (Bachelor's or Master's).*

[b] *P-value for each subgroup was measured using a non-parametric equality test for median scores.*

[c] *Two participants were excluded from the employment status analysis, because they were students (so they do not have an employment status).*

6. Discussion

The results of this study showed that the Maithili version of the PSI is a culturally valid tool to measure perceptions of leprosy among community members in Nepal. Negatively loaded phrases in existing stigma measurement tools may unintentionally evoke negative and insensitive emotions or opinions among respondents, potentially reinforcing stigma towards persons affected by leprosy. Therefore, a new stigma measurement instrument, the Positive Stigma Inquiry, was designed. The objective of this study was to prevent reinforcing stigma towards people affected by leprosy, by assessing the cultural validity of the PSI for measuring leprosy-related stigma in the context of Nepal. This study assessed the semantic, item, operational, and measurement validity of the PSI. Several adaptations such as adding examples to the items, modifying Item 8 and the example for Item 2, were required for a better understanding of the PSI. In addition, the removal of Item 13 improved the measurement validity of the PSI scale. The study's key findings related to the different types of validity will be discussed in this section, along with a reflection on the theoretical framework, and the study's strengths and limitations.

6.1 Semantic validity

During the translation process of the PSI from English to Maithili, only minor adjustments were needed to preserve a similar meaning of the translated words and questions. However, various additional modifications to the PSI were made during and after the qualitative data collection phase since several items were not well understood by all community members. The PSI questions were easier to comprehend for low literate participants when examples were integrated into the items. The Consultation and Relational Empathy (CARE) measure, although targeting healthcare providers, also includes examples in the items to make the questions more understandable for the respondents (Mercer et al., 2004). The same applies for the Screening Activity Limitation and Safety Awareness (SALSA) scale, which provides examples for the items that can be used when participants do not understand the items clearly (SALSA Collaborative Study Group, 2010). Previous validation studies of the WEMWBS scale also added standardised examples to the items to prevent incorrect interpretations (Dijkstra et al., 2024; van der Staaij, 2019). The use of examples in the study by Dijkstra et al. (2024) resulted in better comprehension and correct interpretation of the questions in the WEMWBS, which is in line with our findings.

Additionally, for Item 8 *('Would the family member of a person with leprosy feel comfortable talking about it to their friends?')*, it seemed unclear for the respondents whether the question referred to the family member or the person affected talking to their friends. With an indirect question, it is possible that community members may have difficulty distinguishing between the affected person and his/her family members (Ruytenbeek, 2017). Based on this, Item 8 was revised into: *'Would a family member feel comfortable telling others that someone in the family has leprosy?'*. Additionally, we found that four participants did not use the term *'living near'* or a synonym in their paraphrases for Item 2 *('Would a community member feel comfortable living near a person with leprosy?')*. These participants used words as *'be around'*, *'sit with'*, *'go near'*, or *'gather around'* in their paraphrases, because the term *'living near'* in Maithili has various definitions. This finding is in agreement with the suggestion by Stevelink & van Brakel (2013), namely that an inadequate translation of words or questions in validation studies may result in confusion among the participants, challenges in the administration of the scale, or the original meaning of words or items being lost. It is essential that corresponding words or items, in this case English versus Maithili, have comparable meanings (Sperber, 2004). The SALSA manual for instance describes that multiple terms from the original instrument can be translated as the same term in a certain local language (SALSA Collaborative Study Group, 2010). Although, it can also go vice versa; the meaning of certain translated words in the local language may have multiple definitions. To solve this issue, we decided to change the example for Item 2 into: *'Would someone feel comfortable being a neighbour of a person with leprosy?'*, since there was no better alternative than the Maithili term that was used in the PSI for *'living near'*. All these improvements led to an increased semantic validity of the PSI scale, ensuring that the wording and items were suitable and well understood without additional explanations.

6.2 Item validity

Most participants considered all thirteen PSI items relevant and acceptable to their culture and situation and felt comfortable responding to the questions. One respondent mentioned that Items 11 *('Would an employer be willing to hire a person with leprosy?')* and 12 *('Would people be willing to buy food from a person affected by leprosy?')* were irrelevant to his community, because employers will not hire someone with leprosy since they might risk losing other employees, and people in his community would not buy any food at all from a person with leprosy. The respondent's answer demonstrates that there is still stigma present towards people who have leprosy in his community. Previous studies in Nepal showed that people affected by leprosy are frequently excluded from jobs (Adhikari et al., 2013; Calcraft, 2006; Marahatta et al., 2018), but are also not hired to new jobs simply because of their visible impairments (Calcraft, 2006; de Stigter et al., 2000; Nicholls & Smith, 2002). This indicates that stigma still has a negative impact on employment of persons affected, resulting in fewer opportunities to earn money, which would contribute to poverty (Calcraft, 2006; Nicholls & Smith, 2002). For that reason, we have decided not to change or exclude these items, because it is essential to measure the impact of stigma on employment opportunities. Another reason for not changing or excluding the two items is because other participants considered them relevant and there were no additional justifications for modifying Items 11 and 12. All these findings together indicate a positive item validity of the PSI.

6.3 Operational validity

No adjustments were made to the format of the PSI because most participants understood the answer options and instructions and mentioned that the different answer options fit the items. The response scale of the PSI is based on the Likert-type response scale used by the WEMWBS. Van der Staaij (2019) cross-culturally validated the WEMWBS scale in India, and most respondents understood the different answer options, which is in line with our findings. Dijkstra et al. (2024) suggested adding a visual element to the answer options in the Likert response scale, such as symbols, because respondents in her study were confused about the two stigma tools that used different response scales. The use of symbols might help the respondents' interpretation of the response scale, particularly when multiple health-related stigma instruments with different response scales are employed in a study (Dijkstra et al., 2024). However, in our study there was no confusion among participants regarding the response scales, and therefore no alterations were made.

The interviewer-administered approach of the PSI was also appropriate, since most of the participants had low literacy levels. Previous validation studies (the EMIC-CSS in Tanzania and the Participation Scale Short Simplified (PSSS) in Indonesia) with high numbers of illiterate people in their study population also used the interviewer-administered mode (Klinker et al., 2023; Coltof, 2019). Peters et al. (2014) used a combination of interviewer- and self-administered approach for filling in the EMIC-CSS and SDS forms. This was also a possible option for our study since there were numerous respondents with higher literacy levels in the quantitative study phase. We did not, however, change the administration mode to a combination of interviewer- and self-administered as in the study of Peters et al. (2014), because the Maithili language consists of multiple dialects. Because of the differences in dialects, there is the possibility that respondents might misunderstand the PSI items when using a self-administered approach. Adopting a single administration approach also provides consistency, whereas using a mix of administration methods may result in a reduced consistency across respondents. All these findings together suggest a positive rating for operational validity of the PSI scale.

6.4 Measurement validity

The *internal consistency* of the PSI for all thirteen items was 0.851 but slightly increased to 0.869 when Item 13, which showed a low item-to-total correlation, was removed from the scale. Cronbach's alpha should be between 0.70 – 0.95, thus an *internal consistency* of 0.869 (excluding Item 13) is considered very good. A statistically significant correlation was observed between the PSI and SDS ($r = 0.403$, $p < 0.05$), and although not significant, a weaker correlation also existed between the PSI and EMIC-CSS ($r = 0.208$, $p = 0.073$). The correlation between the PSI and SDS ($r = 0.402$) is sufficient, since the SDS assesses the respondent's view and the PSI the perceived attitude and behaviour of other community members. The smaller sample size for the EMIC-CSS ($n = 50$) compared to the PSI ($n = 100$) could explain the non-significant and weaker correlation between the two scales. The predefined hypotheses stated that there would be a positive, significant, but not very strong correlation between the PSI and SDS/EMIC-CSS sum scores. Although the correlation between the PSI and EMIC-CSS sum scores was not statistically significant at the 5% level, it was near significant, and thus we still rated this positively with regards to the *construct validity* for the PSI. However, increasing the sample size for the EMIC-CSS interviews to $n = 100$ could improve the assessment of *construct validity*.

The inter-interviewer *reliability* of the PSI ($ICC_{agreement}$) was 0.77 for 48 repeat interviews. Terwee et al. (2007) suggested that the ICC should be ≥ 0.70. With a coefficient of 0.77, the PSI can be considered as reliable because the concordance level between the first and second (repeat) interview is high. The SDC_{group} (2.13) of the PSI was smaller than the SDC_{ind} (14.77), indicating that minor score differences are adequate for showing changes at the group level, whereas major score differences are needed at the individual level. A lower value for SDC_{group} indicate a relatively small measurement error and thus a good capability of the PSI to distinguish actual changes or differences in scores from measurement error. This finding is in line with other scale validation studies reporting smaller values for SDC_{group} compared to SDC_{ind} (Peters et al., 2014; van der Staaij, 2019).

Interpretability means understanding the PSI sum scores between the different subgroups (see Table 12 in Chapter 5). The median score for males (36.0) was significantly ($p = 0.021$) higher than for females (30.0) in our study, showing that males may have more negative perceptions of leprosy. However, this is not in line with previous studies demonstrating higher (mean) scores for females compared to males (Dijkstra et al., 2024; Peters et al., 2014; Singh et al., 2019). The lower median score for females in our study could be explained by the possibility that they provided socially desirable answers rather than their honest and true opinions. Other community/family members were occasionally present during the interviews, which could have influenced this outcome (van der Staaij, 2019). Previous studies showed that participants with low literacy levels had more negative perceptions of leprosy compared to participants with high literacy levels (Adhikari et al., 2014; Kaehler et al., 2015; Rao et al., 2008; Singh et al., 2019; Urgesa et al., 2020). In our study, however, no statistically significant difference was found between low- and high literate respondents. This outcome may be influenced by low literate participants potentially providing socially desirable answers. For instance, this group of individuals may believe they are in a lower position than the interviewer, and therefore, they provide socially desirable answers out of insecurities. Another possible explanation for the non-significance could be that high literate participants are more aware to provide honest and true opinions on sensitive questions or topics during an interview.

6.5 Reflection on theoretical framework

Cross-cultural validation of new or adapted health-related stigma scales is essential because concepts, such as *'stigma'*, might be interpreted differently across cultures. For that reason, instruments intended for use in another culture need to be first validated cross-culturally (Stevelink & van Brakel, 2013), and the model of equivalence proposed by Herdman et al. (1998) is often used for scale validation processes. While this process may seem simple and uncomplicated, it is actually relatively complex (Peters et al., 2014). The review by Bowden & Fox-Rushby (2003) examined the translation and validation process of nine health-related quality of life (HRQL) tools that used Herdman et al.'s (1998) equivalence model (Bowden & Fox-Rushby, 2003). Interestingly, the review found that the assessment of the five equivalence categories (conceptual, item, semantic, operational, and measurement) for the nine HRQL instruments was often insufficient (Bowden & Fox-Rushby, 2003; Stevelink & van Brakel, 2013).

Stevelink & van Brakel (2013) adjusted Herdman et al.'s (1998) framework by incorporating the psychometric properties specified by Terwee et al. (2007) to conduct an in-depth assessment of measurement equivalence. Several studies have used this adapted version for cultural equivalence assessments of new scales (Dijkstra et al., 2024; Peters et al., 2014; Peters et al., 2017). It seems that the adapted framework by Stevelink & van Brakel (2013) focusing on the five cultural equivalence categories, including the psychometric properties, contributes to improving the quality of the cross-cultural validation process of new instruments. This subsequently guarantees reliable and valid scales across cultures/countries (Stevelink & van Brakel, 2013). However, this is the very first validation study for the PSI scale. Therefore, the term equivalence was altered into "validity" for each domain (semantic, item, operational, and measurement validity) using the newly developed definitions indicated in Table 1. Although the newly formed definitions had no substantive impact, it was semantically relevant to use the term "validity" because the equivalence concepts were not applicable to this study. The framework by Stevelink & van Brakel (2013), using the newly developed definitions of the cultural validity domains, was beneficial for this validation study to provide a clear direction for measuring and provided a detailed description of the PSI's validity in the context of leprosy in Nepal.

6.6 Strengths and limitations

This study has various strengths and limitations. One fundamental strength is that this study used a validated theoretical framework, as it has been employed in previous validation studies (Dijkstra et al., 2024; Peters et al., 2014). This framework serves as an evident structure to examine the validity of new stigma assessment tools. The newly developed definitions of the cultural validity domains could also be considered as a strength, as they were originally unknown and have therefore a contribution to the literature.

A limitation could be that the in-depth interviews were conducted by a research assistant with limited experiences in qualitative research, which may lead to insufficient and inaccurate in-depth information from the respondents (Dijkstra et al., 2024). To minimise the impact of this limitation, the research assistant received an extensive training prior to data collection, which covered the study's background, qualitative and quantitative research methodology, and interview practices. Also, triangulation of data collection methods can reduce this limitation's impact on the study, as this can guarantee valid and reliable data (Dijkstra et al., 2024). However, participants occasionally expressed their frustrations and insecurities during the interviews, and consequently, the research assistant sometimes felt uncomfortable to ask follow-up questions as instructed. This resulted in information with less depth than desirable.

Another limitation of this study could be the potential presence of social desirability bias, which occurs when participants provide favourable answers and thereby conceal their honest or true opinions (Gower et al., 2022). Most participants reported that the PSI items were easy to understand and that there were no unclear words in the questions. However, it is possible that the respondents provided a socially desirable answer or were embarrassed to admit they did not comprehend the items. Fisher (1994) describes that an in-depth interview approach minimises the social desirability issue, because respondents may provide extensive information. Many respondents in our study, however, provided limited detailed information. This could be due to the research assistant's limited experience in conducting in-depth interviews, or because participants were unsure how to respond due to insecurities. It is also possible that community members who participated in this study, did not feel completely at ease providing honest responses in the presence of the study's researcher (who may be perceived as an outsider). However, the researcher's presence was necessary to observe the local research assistant during data collection, addressing any questions or unclarities, and ensuring the quality of data.

Furthermore, the smaller sample size for the EMIC-CSS could also be considered as a limitation. One reason for the smaller sample size was that the research assistant struggled to read the three questionnaires aloud to all respondents, particularly during high temperatures. In addition, some participants complained about the length of the interview (all three questionnaires) and the comparability of the PSI and EMIC-CSS items. Therefore, it was decided to reduce the EMIC-CSS interviews, because the SDS is considered the most neutral and thus essential for analysing its correlation with the PSI. Nevertheless, the reduced sample size for the EMIC-CSS may have resulted in a non-significant correlation between the PSI and EMIC-CSS sum scores.

6.7 Recommendations for future research

This is the first cross-cultural validation study for the PSI, thus additional research is necessary with other target groups and in other cultural/language settings. Additional research is also required to assess the *responsiveness* of the PSI, as this was not done due to time constraints, and to conduct more EMIC-CSS interviews because the sample size for this scale was smaller (n = 50) compared to the PSI and SDS (n = 100 for both). We validated the PSI in Maithili because most community members in the Terai region of South-East Nepal speak Maithili and are not fluent in Nepali. This, however, means that the PSI scale in Maithili is not applicable for the total population in Nepal, as people outside the Terai region do not speak Maithili. To further build on our research, the PSI should also be validated in Nepali, so the scale can be used for stigma assessments in other parts of Nepal. It is also essential to validate the PSI among community members in a different culture, to examine what their opinions and perspectives are regarding the PSI items. Additionally, we validated the PSI in the field of leprosy, but the PSI is intended to be used to measure health-related stigma in general. Therefore, the PSI should also be validated for other stigmatised health conditions.

Furthermore, with the present study we could not completely answer a part of the research objective; whether the PSI prevents the reinforcement of stigma towards persons affected by leprosy. However, this study does contribute to it by improving stigma assessment tools. To measure whether the PSI indeed prevents the reinforcement of stigma, it is recommended to conduct the PSI in one and the EMIC-CSS in another study sample. The negatively phrased items in the EMIC-CSS differs from the PSI and thus, this scale could be used for assessing the difference in the reinforcement of stigma.

Additionally, it could be helpful to conduct focus groups in the future to gain in-depth information from community members in an interactive setting. This method may provide new findings related to the comprehension, relevancy, acceptability, and comfortability of the PSI items. However, it is also possible that focus groups may not be beneficial in studies focussing on sensitive topics. This may lead to discomfort and distress among participants, making it challenging to gain in-depth information. In this case, the researcher should be skilled to provide a safe and supportive environment and to be conscious of triggers for instance (Focus Groups | Definition, Process, Pros & Cons, 2024).

6.8 Conclusion

In this study we answered the main research question: *To what extent is the Positive Stigma Inquiry (PSI) a culturally valid measurement tool for assessing leprosy-related stigma among community members in Nepal?* Our findings showed that the PSI has good item and operational validity. Semantic validity was achieved by incorporating examples to each item, as well as revising Item 8 and the example for Item 2 for an improved comprehension among community members. In addition, the PSI's measurement validity was optimised by removing Item 13 from the scale. However, more EMIC-CSS interviews are necessary to improve the assessment of *construct validity* for the PSI. Altogether, this study's findings suggest that the PSI is culturally valid and thus an appropriate scale for assessing leprosy-related stigma among Maithili-speaking community members in the Terai region. Although, more research is needed to verify this, to make the scale suitable for Nepal’s entire population, and to assess its validity in other cultural or stigmatised health contexts. Aside from that, this study provides a significant contribution to improving stigma assessment tools.

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Appendix I: The equivalence concepts

The model of equivalence by Stevelink & van Brakel (2013), adjusted from the framework developed by Herdman et al. (1998), has been discussed in Chapter 3. In the following, additional discussions regarding the equivalence concepts can be found.

Conceptual equivalence

Conceptual equivalence examines whether the instruments have a comparable relationship to the concept that is being studied and the emphasis assigned upon various domains of the concept. This indicates that concepts may have distinct conceptualisations across different cultural groups. Conceptual equivalence is feasible when instruments have the same link to the underlying concept across different cultures (Harachi et al., 2006; Herdman et al., 1998; Lee et al., 2021; Stevelink & van Brakel, 2013; Zaragoza-Salcedo et al., 2023).

Item equivalence

Item equivalence refers to the varying relevance and acceptability of items across different cultures. The relevance of items means that certain questions that ask about a specific topic in one culture, may not be relevant in another culture. For instance, questions about the use of a specific medicine are not relevant in cultures where this medication do not exist. The acceptability of items indicates that certain questions might be insulting to the target group or are related to taboo topics. If this is the case, the items should be revised and tested again before it can be applied in practice. Item equivalence can be achieved when items in questionnaires are equally relevant, acceptable, and understandable among different cultural contexts (Herdman et al., 1998; Lee et al., 2021; Stevelink & van Brakel, 2013).

Semantic equivalence

Semantic equivalence refers to the instrument having the same meaning in different languages, in order to achieve a comparable result on respondents speaking different languages. Thereby, it is important to use language within questionnaires that is understandable to the target group (Herdman et al., 1998; Lee et al., 2021; Stevelink & van Brakel, 2013).

Operational equivalence

Operational equivalence concerns the use of the same questionnaire format, instructions, administration, and measurement methods between the adapted and original health-related instrument. This domain can be achieved when these elements do not have an impact on the results (Herdman et al., 1998; Lee et al., 2021; Stevelink & van Brakel, 2013). For instance, it is not logical to induce a visual analogue scale within the questionnaire if community members are not familiar to viewing maps of their local area (Herdman et al., 1998).

Measurement equivalence

Measurement equivalence is to assure that the psychometric properties between various language versions of the same instrument are similar to each other (Herdman et al., 1998; Lee et al., 2021; Stevelink & van Brakel, 2013). This indicates that the psychometric properties between different language versions of a questionnaire should be comparable in order to achieve measurement equivalence. The psychometric properties, as defined by Terwee et al. (2007), were explained in the *theoretical background* (see section 3.2).

Cultural equivalence

The study by Herdman and colleagues (1998) defines functional equivalence as the degree to which an instrument is intended to perform equally effective among different cultures. However, the study of Stevelink & van Brakel (2013) suggests that this equivalence should be named cultural equivalence, combining the five previous mentioned equivalences (conceptual, item, semantic, operational, and measurement) under this domain. Cultural equivalence can be defined as the degree to which a new instrument is equally applicable across multiple cultures (Stevelink & van Brakel, 2013), and can be reached when the conceptual, item, semantic, operational, and measurement equivalences have been achieved.

Appendix II: Informed consent forms

II.I Informed consent form for interviews

Co-investigators: Dunya Selemangel & Crystal Kerkhoven

Organizations: Nepal Leprosy Trust (NLT) and NLR

Title of the study: Cultural validation of the Positive Stigma Inquiry (PSI) by measuring leprosy-related stigma among community members in Nepal.

Introduction: The aim of the study is to get more insight into leprosy-stigma among community members and healthcare workers. The results of the study are important for the health services in Nepal to help people with leprosy in the future. We will ask you about your perspective related to the new form. If you feel that the questions are too personal, or if you prefer to skip a question, please let us know.

Voluntary participation: Your participation in this research is voluntary, which means that you can decide to stop at any moment and without a reason. You will not receive any money or other resources for your participation in this study.

Procedures and confidentiality: The interview will take around 45 – 60 minutes. This interview will be audio recorded if you give permission. To protect your privacy, the information of this interview will be anonymized, and we will not share your information with anyone outside the research team. The information will be stored in a safe place and the audio recording will be deleted accordingly after transcribing.

Contact: Do you have any questions? For questions and more information please do not hesitate to contact us. Lalgadh Leprosy Hospital & Services Centre. Lalgadh, Mithila Municipality-10, Dhanusha District, Province-2, Nepal. +97715151322.

Consent: I have understood the information, and the researcher has answered my questions. I know I can end my participation in this study at any given time. I am a voluntary participant in this study.

Researcher: I have clearly and thoroughly educated the participant on the nature, methods, and purpose of the study. I have answered any potential questions that the participant may have regarding the research.

Date: ___________________________

Signature Participant **Signature Researcher**

___________________________ ___________________________

Thank you very much for participating in this study.

II.II Informed consent form for questionnaires

Co-investigators: Dunya Selemangel & Crystal Kerkhoven

Organizations: Nepal Leprosy Trust (NLT) and NLR

Title of the study: Cultural validation of the Positive Stigma Inquiry (PSI) by measuring leprosy-related stigma among community members in Nepal.

Introduction: The aim of the study is to get more insight into leprosy-stigma among community members and healthcare workers. The results of the study are important for the health services in Nepal to help people with leprosy in the future. We will ask you to fill in this questionnaire about your thoughts related to leprosy. If you feel that a question is too personal, please let us know, and we will skip this question.

Voluntary participation: Your participation in this research is voluntary, which means that you can decide to stop at any moment and without a reason. You will not receive any money or other resources for your participation in this study.

Procedures and confidentiality: The interview related to the questionnaire will take around 30 – 45 minutes. We will fill in your answers on the questionnaire form. To protect your privacy, the information will be anonymized, and we will not share your information with anyone outside the research team. The information will be stored in a safe place.

Contact: Do you have any questions? For questions and more information please do not hesitate to contact us. Lalgadh Leprosy Hospital & Services Centre. Lalgadh, Mithila Municipality-10, Dhanusha District, Province-2, Nepal. +97715151322.

Consent: I have understood the information, and the researcher has answered my questions. I know I can end my participation in this study at any given time. I am a voluntary participant in this study.

Researcher: I have clearly and thoroughly educated the participant on the nature, methods, and purpose of the study. I have answered any potential questions that the participant may have regarding the research.

Date: ___________________________

Signature Participant	**Signature Researcher**
___________________________	___________________________

Thank you very much for participating in this study.

Appendix III: Socio-demographic form

General	
Name of data collector/interviewer	
Date of interview	
Participant information	
Participant ID	
Phone number	
Municipality - Ward no.	
Name of village	
Age of participant	
Sex	○ Male ○ Female ○ Other: ____________________ ○ Prefer not to say / do not know
Religion	○ Hinduism ○ Buddhism ○ Islam ○ Christianity ○ Other: ____________________ ○ Prefer not to say / do not know
Education	○ No schooling ○ Primary school (5th) ○ Middle school (8th) ○ High school (10th) ○ Higher secondary (12th) ○ Tergraduate schooling ○ Other: ____________________ ○ Prefer not to say / do not know
Current employment status	○ Unemployed ○ Home maker ○ Self-employed ○ Service-holder ○ Labour work ○ Student ○ Retired

	○ Other: ___________________ ○ Prefer not to say / do not know
Marital status	○ Currently married ○ Widow(er) ○ Divorced ○ Separated ○ Single / never married ○ Prefer not to say / do not know
Living situation	○ With family in village ○ Alone in village ○ Designated colony / segregated area ○ Homeless ○ Other: ___________________ ○ Prefer not to say / do not know

Appendix IV: Semi-structured interview guide

1. Introduce ourselves

The research assistant introduces him/herself and the study's researcher to the interviewee prior to the interview and subsequently thank the respondent for their willingness to participate in this study.

Thank you for participating in this study. This is [...], a student from the Netherlands and responsible for this project. My name is [...] and I will conduct this interview together with [...]. I will guide you through the interview because I am a native Maithili speaker.

2. Introduce study and interview

The local research assistant explains the aim of the study and the procedure of the interview to the respondent.

"*The aim of the study is to get more insight into leprosy-stigma among community members. The results of the study are important for the health services in Nepal to help people with leprosy in the future. We will ask you about your perspective and thoughts related to the new form. This interview will help us find out if the questionnaire can be used in Nepal. The interview will take around 45 minutes in total. There are no right or wrong answers. If you feel that a question is too personal, or if you prefer to skip a question, please let us know and we will skip the question."*

3. Ask for informed consent

The research assistant will read the informed consent form to the respondent. The respondent can ask questions if something is unclear. The research assistant provides the respondent the answers when needed.

Do you give permission to participate in this study? [If permission is given, the respondent's signature or thumb print from the respondent is collected].

Do you give permission to audio-record the interview?

4. Fill in respondent's personal information

Ask questions concerning their personal information (see socio-demographic form).

First, we need some personal information from you. [Fill in socio-demographic form].

5. Ask for further questions

Now that we have discussed the informed consent and the socio-demographic form, do you have any questions for me? If not, then I will start recording.

Start recording

Explain procedure and answer options

"This interview consists of two parts. For the first part of the interview, we will go through the questionnaire. We will read each question out loud to you in Maithili. After each question, we will ask you additional questions. In the second part of the interview, we will ask you some general questions about your opinion regarding the questionnaire and the answer options in the questionnaire. The answer options for each question are 'none of the time, rarely, some of the time, often, all the time and I don't know'."

Instructions for the interviewer:

- If the respondent does not answer the question, or does not understand the question, the question should be repeated in the same way.
- If the respondent still does not answer or does not understand the question, use the Q/Q to guide the question further.
- The questions should not be paraphrased or translated during the interview.
- If the individual goes off-topic, gently guide them back to the question and kindly remind them that they can discuss possible issues or topics at the end of the interview.
- If the respondent does not feel comfortable with answering a question, her/she is not obligated to.

Part I: Semantic and item validity

After each question, the following questions will be asked:

Interviewer reads the question from the PSI scale out loud to the participant

1. Can you repeat the question in your own words?
    a. If the respondent uses the exact same words/phrases as in the item: Can you give an example?
2. Did you find the question easy to understand?
    a. If no: Why was it difficult to understand the question? Do you know what could be changed to make the question clearer to you?
3. Were any words in the question unclear to you?
    a. If yes: Which words were unclear?
        i. Do you know which words could be changed to make the question clearer to you?
4. Do you think this question is relevant for you and other community members?
    a. If yes: Why? Can you give an example?
    b. If no: Why? Can you give an example why not?
5. Would you feel comfortable with answering this question if you had to?
    a. If yes: Why would you feel comfortable?
    b. If not: Why would you not feel comfortable?
        i. Were there any words, phrases or statements in the question that made you feel uncomfortable?
        ii. Do you know what could be changed to make the question more comfortable?

Part II: Operational validity

After completing all the questions, the following questions will be asked:

The interviewer reads the instructions and different answer options (none of the time, rarely, some of the time, often, all the time, I don't know) from the PSI scale out loud to the participant.

1. What did you think of the questionnaire?
2. Did you understand the different answer options?
    a. If not: Why were the answer options not clear to you?
        i. Do you know what could be changed to make the answer options clearer to you?
3. Do you think the answer options suit the questions well?
    a. If not: Why?
        i. Do you know what could be changed to make the answer options suit the question better?
4. Did you understand the instructions of the questionnaire?
    a. If not: Why?
        i. Do you know what could be changed to make the instructions clearer to you?
5. Do you think this questionnaire is relevant for you and other community members?
    a. If yes: Why?
    b. If not: Why not?
6. Did you feel comfortable during this interview?
    a. If no: Why not?
        i. Were there any specific questions or words that made you feel uncomfortable?
        ii. Which question(s)/word(s)?
        iii. Can you explain why this specific question or word made you feel uncomfortable?
7. Do you have any other remarks/comments or questions about the questionnaire?
8. Did we forget anything important during the interview that you think should be mentioned?
9. Do you have any questions?

"This was the last question in the interview. Thank you for taking the time to participate and for sharing your answers with us. We appreciate your willingness to participate in this study."

Stop recording

Appendix V: Positive Stigma Inquiry

V.I The first English version of the PSI

Instructions for filling in the questionnaire

This questionnaire consists of a general scale of thirteen items for assessing health-related stigma among community members and a separate sub-scale of five items for assessing health-related stigma among healthcare workers.

Each question has five response options:
None of the time: It never happens
Rarely: It happens on rare occasions or has happened only one time
Some of the time: It happens consistently from time to time
Often: It is common and has repeatedly happened
All the time: It always happens
I don't know: The participant does not know if or how many times it happens

Please, choose the option that best fits your opinion and fill in the appropriate box accordingly.

Scale for assessing community member health-related stigma							
Item	**Question**	**None of the time**	**Rarely**	**Some of the time**	**Often**	**All the time**	**I don't know**
		5	**4**	**3**	**2**	**1**	**0**
1.	Would a person with [condition] be willing to tell others about their condition?						
2.	Would a community member feel comfortable living near a person with [condition]?						
3.	After finding out that a person has [condition], would a community member have the same (or more) respect towards this person?						
4.	Would other people in your community be willing to interact with a person affected by [condition]?						
5.	Would people be willing to visit the home of a person affected by [condition]?						
6.	Would people in your community respect the family of a person with [condition]?						
7.	Would the family of a person with [condition] be accepted in the community?						
8.	Would the family member of a person with [condition] feel comfortable talking about it to their friends?						
9.	Would a community member be willing to marry a person with [condition]?						

10.	Would a community member be willing to marry a relative of a person with [condition]?						
11.	Would an employer be willing to hire a person with [condition]?						
12.	Would people be willing to buy food from a person affected by [condition]?						
13.	How often is the name of [condition] used instead of the person's own name when people talk about him/her?						
Sub-scale for assessing health care provider health-related stigma							
14.	Would the care of a patient who has/had [condition] be considered a "respectable job"?						
15.	At the health facility, would health care providers be comfortable touching someone with [condition]?						
16.	Are patients with wounds or disabilities due to [condition] treated in the same treatment room or ward as other patients? *****						
17.	Would you use different protective measures when treating patients with [condition] as you would for patients with other infectious diseases? (e.g., tuberculosis)						
18.	Would you feel comfortable diagnosing or managing [condition] cases at your health care facility?						

***May not be relevant for all NTDs**

V.II The English version of the PSI used for the quantitative phase

Instructions for filling in the questionnaire

This questionnaire consists of a general scale of thirteen items for assessing health-related stigma among community members and a separate sub-scale of five items for assessing health-related stigma among healthcare workers.

Each question has six response options:
None of the time: It never happens
Rarely: It happens on rare occasions or has happened only one time
Some of the time: It happens consistently from time to time
Often: It is common and has repeatedly happened
All the time: It always happens
I don't know: The participant does not know if or how many times it happens

Please, choose the option that best fits your opinion and fill in the appropriate box accordingly.

Scale assessing community perception towards leprosy

Item	Question	None of the time	Rarely	Some of the time	Often	All the time	I don't know
		5	4	3	2	1	0
1.	Would a person with [condition] be willing to tell others about their condition? For example, would someone with leprosy tell other people that he/she has leprosy?						
2.	Would a community member feel comfortable living near a person with [condition]? For example, would someone feel comfortable being a neighbour of a person with leprosy?						
3.	After finding out that a person has [condition], would a community member have the same (or more) respect towards this person? For example, would someone acknowledge a person with leprosy and say hello to them when they meet them?						
4.	Would other people in your community be willing to interact with a person affected by [condition]? For example, would someone have a conversation with a person with leprosy?						
5.	Would people be willing to visit the home of a person affected by [condition]? For example, would someone go to the home of a person with leprosy to drink tea?						
6.	Would people in your community respect the family of a person with [condition]? For example, would people in the community ask for the						

	opinion of the family of a person with leprosy?						
7.	Would the family of a person with [condition] be accepted in the community? For example, would people in the community invite the family of a person with leprosy to community events?						
8.	Would a family member feel comfortable telling others that someone in the family has [condition]? For example, would someone feel at ease telling his/her friends that his/her brother or sister has been diagnosed with leprosy?						
9.	Would a community member be willing to marry a person with [condition]?						
10.	Would a community member be willing to marry a relative of a person with [condition]? For example, would a person marry the brother/sister of someone with leprosy?						
11.	Would an employer be willing to hire a person with [condition]? For example, would a school hire a person with leprosy to work as a schoolteacher?						
12.	Would people be willing to buy food from a person affected by [condition]? For example, would someone buy vegetables from a person with leprosy?						
13.	How often is the person's own name used instead of the name 'leprosy patient' when people talk about him/her? For example, saying kustharogi instead of Ram Prakash?						

V.III The (final) English version of the PSI following the quantitative analysis

Instructions for filling in the questionnaire

This questionnaire consists of a general scale of thirteen items for assessing health-related stigma among community members and a separate sub-scale of five items for assessing health-related stigma among healthcare workers.

Each question has six response options:
None of the time: It never happens
Rarely: It happens on rare occasions or has happened only one time
Some of the time: It happens consistently from time to time
Often: It is common and has repeatedly happened
All the time: It always happens
I don't know: The participant does not know if or how many times it happens

Please, choose the option that best fits your opinion and fill in the appropriate box accordingly.

Scale assessing community perception towards leprosy							
Item	**Question**	**None of the time**	**Rarely**	**Some of the time**	**Often**	**All the time**	**I don't know**
		5	**4**	**3**	**2**	**1**	**0**
1.	Would a person with [condition] be willing to tell others about their condition? For example, would someone with leprosy tell other people that he/she has leprosy?						
2.	Would a community member feel comfortable living near a person with [condition]? For example, would someone feel comfortable being a neighbour of a person with leprosy?						
3.	After finding out that a person has [condition], would a community member have the same (or more) respect towards this person? For example, would someone acknowledge a person with leprosy and say hello to them when they meet them?						
4.	Would other people in your community be willing to interact with a person affected by [condition]? For example, would someone have a conversation with a person with leprosy?						
5.	Would people be willing to visit the home of a person affected by [condition]? For example, would someone go to the home of a person with leprosy to drink tea?						
6.	Would people in your community respect the family of a person with [condition]? For example, would people in the community ask for the						

	opinion of the family of a person with leprosy?						
7.	Would the family of a person with [condition] be accepted in the community? For example, would people in the community invite the family of a person with leprosy to community events?						
8.	Would a family member feel comfortable telling others that someone in the family has [condition]? For example, would someone feel at ease telling his/her friends that his/her brother or sister has been diagnosed with leprosy?						
9.	Would a community member be willing to marry a person with [condition]?						
10.	Would a community member be willing to marry a relative of a person with [condition]? For example, would a person marry the brother/sister of someone with leprosy?						
11.	Would an employer be willing to hire a person with [condition]? For example, would a school hire a person with leprosy to work as a schoolteacher?						
12.	Would people be willing to buy food from a person affected by [condition]? For example, would someone buy vegetables from a person with leprosy?						

V.IV The first Maithili version of the PSI

सकारात्मक कलंक पुछताछ (PSI) प्रोटोटाईप

निच्चा देल गेल प्रश्नावली भर कें निर्देशन सभः

अपन सब कें समुदाय आ स्वास्थ्यकर्मी कें बिच प्रचलित किछ स्वास्थ्य सम्बन्धी कलंक सभ अई प्रश्नावली मे देल गेल अछि। जाहि मे सं १३ टा समुदाय कें व्यक्ति सब कें लेल अछि आउर ५ टा स्वास्थ्यकर्मी सभक लेल।

प्रत्येक प्रश्न मे पांच टा उत्तर विकल्प मेअछि :

कखनो नाहि : कहियो नहि होयत छैक

शायदे कहियो : ई दुर्लभ अवसर पर होइत अछि या मात्र एक बेर भेल अछि

कहियोकाल : समय समय पर लगातार होइत रहैत अछि

अक्सर : ई आम बात अछि आ बेर बेर होइत रहल अछि

सब समय : सदिखन होइत छैक

हमरा नाई बुझल अछि : उत्तरदाता कें नहि बुझल छैक जे ई होइत छैक या कतेक बेर होइत छैक

आहां कें विचार मे जे सही बुझाइय कृपया सें हे विकल्प मे टिक लगायल जाय।

समुदाय कें व्यक्ति कें स्वास्थ्य सं सम्बन्धित कलंक कें मूल्याकंन कें लेल स्केल							
संख्या	**प्रश्न**	**कखनो नाहि**	**शायदे कहियो**	**कहियोकाल**	**अक्सर**	**सब समय**	**हमरा नाई बुझल अछि**
		५	४	३	२	१	०
१.	कि प्रभावित व्यक्ति अपन (कुष्ठरोग) कें बारे में दोसर कें बताबय लेल तैयार हेताह ?						
२.	कि समुदायके कोनो व्यक्ति (कुष्ठरोग) लागल व्यक्ति कें नजदिक रहय में सहज महसुस करतय ?						
३.	कोनो व्यक्ति कें ओकर (कुष्ठरोग) कें बारेमे पता चलला कें बाद, की समुदाय कें दोसर व्यक्ति कें एहि व्यक्ति कें प्रति ओतबे (या बेसी) समान होयतै ?						
४	की अहां कें समुदाय कें अन्य व्यक्ति सब (कुष्ठरोग) सं प्रभावित व्यक्ति सं बातचीत करय कें लेल ईच्छुक होयतै ?						
५.	की लोक सब (कुष्ठरोग) सं प्रभावित भेल व्यक्ति कें घर जेबाक लेल ईच्छुक हेताह ?						
६.	की अहां कें समाज कें लोक सब (कुष्ठरोग) लागल व्यक्ति कें परिवार कें सम्मान करतै ?						

७.	की (कुष्ठरोग) लागल व्यक्ति कें परिवार कें समाज में स्वीकार केल जायत ?						
८.	की (कुष्ठरोग) लागल व्यक्ति कें परिवार कें सदस्य अपन दोस्तक सं अइ बारे मे बात करय में सहज महसुस करतय ?						
९.	की कोनो समुदाय कें व्यक्ति (कुष्ठरोग) लागल व्यक्ति सं विवाह करय लेल ईच्छुक हेताह ?						
१०	की कोनो समुदाय कें व्यक्ति (कुष्ठरोग) लागल व्यक्ति कें रिश्तेदार सं विवाह करय कें लेल ईच्छुक होयतै ?						
११.	की कोनों रोजगारदाता (कुष्ठरोग) लागल व्यक्ति कें काम पर रखबाक लेंल ईच्छुक होयतै ?						
१२.	की लोक सब (कुष्ठरोग) सं प्रभावित व्यक्ति सं भोजन खरीदय कें लेंल ईच्छुक हेताह ?						
१३.	लोक सब बात करैय बेर में व्यकित कें नाम कें सट्टा ओकरा (कोढी) कें नाम ल क कतेक बेर प्रयोग कयल जाइत अछि ?						
स्वास्थ्य देखभाल प्रदायकद्धारा स्वास्थ्य संसम्बन्धित कलंक कें मूल्याकंन कें लेल उप मापन							
१४.	की कोनो रोगी कें जेकरा (कुष्ठरोग) लागल छै वा छलै, ओकरा देखभाल केनाय “सम्मानजनक काज” मानल जेतय ?						
१५.	स्वास्थ्य संस्था मे, की स्वास्थ्य सेवा प्रदायक कें ʿ (कुष्ठरोग) लागल व्यक्ति कें स्पर्श करएय में सहज होयतै ?						
१६.	की (कुष्ठरोग) कें कारण घाव वा विकृति भेल रोगी कें इलाज अन्य मरीजक कें समान उपचार कक्ष या वार्ड में कैल जायत छै ?						
१७.	की अहां (कुष्ठरोग) लागल मरीज कें ईलाज करएय कें समय अन्य संक्रामक बिमारी (जेनाः क्षयरोग) जेना सुरक्षात्मक उपाय सब अपनाबय छी ?						
१८.	की अहां अपन स्वास्थ्य केन्द्र में (कुष्ठरोग) कें निदान वा व्यवस्थापन करय में सहज महसुस करब ?						

* सब NTDs के लेल प्रासंगिक नहि भ सकैत अछि

V.V The Maithili version of the PSI used for the quantitative phase

सकारात्मक कलंक पुछताछ (PSI) प्रोटोटाईप

निच्चा देल गेल प्रश्नावली भर कें निर्देशन सभ:

अपन सब कें समुदाय आ स्वास्थ्यकर्मी कें बिच प्रचलित किछ स्वास्थ्य सम्बन्धी कलंक सभ अई प्रश्नावली मे देल गेल अछि। जाहि मे सं १३ टा समुदाय कें व्यक्ति सब कें लेल अछि आउर ५ टा स्वास्थ्यकर्मी सभक लेल।

प्रत्येक प्रश्न मे छ टा उत्तर विकल्प मेअछि :

 # कखनो नाहि : कहियो नहि होयत छैक

 # शायदे कहियो : ई दुर्लभ अवसर पर होइत अछि या मात्र एक बेर भेल अछि

 # कहियोकाल : समय समय पर लगातार होइत रहैत अछि

 # अक्सर : ई आम बात अछि आ बेर बेर होइत रहल अछि

 # सब समय : सदिखन होइत छैक

 # हमरा नाई बुझल अछि : उत्तरदाता कें नहि बुझल छैक जे ई होइत छैक या कतेक बेर होइत छैक

आहां कें विचार मे जे सही बुझाइय कृपया सें हे विकल्प मे टिक लगायल जाय।

समुदाय में कुष्ठरोग प्रति विचार आकंलन स्केल							
संख्या	**प्रश्न**	**कखनो नाहि**	**शायदे कहियो**	**कहियोकाल**	**अक्सर**	**सब समय**	**हमरा नाई बुझल अछि**
		५	४	३	२	१	०
१.	कि प्रभावित व्यक्ति अपन (कुष्ठरोग) कें बारे में दोसर कें बताबय लेल तैयार हेताह ? उदाहरण के लेल, कि कुष्ठरोग लागल व्यक्ति कियो गोटे के कहतै जे ओकरा कुष्ठरोग लागल अछि?						
२.	कि समुदायके कोनो व्यक्ति (कुष्ठरोग) लागल व्यक्ति कें नजदिक रहय में सहज महसुस करतय ? उदाहरण के लेल, कि कोनो व्यक्ति कुष्ठरोग लागल व्यक्ति के पडोसी भ क रहैय मे सहज महसुस करतैय?						
३.	कोनो व्यक्ति कें ओकर (कुष्ठरोग) कें बारेमे पता चलला कें बाद, की समुदाय कें दोसर व्यक्ति कें एहि व्यक्ति कें प्रति ओतबे (या बेसी) समान होयतै ? उदाहरण के लेल, कि कोनो व्यक्ति कुष्ठरोग लागल व्यक्ति के भेटला पर ओकरा सम्मान कैरक नमस्कार करत ?						
४	की अहां कें समुदाय कें अन्य व्यक्ति सब (कुष्ठरोग) सं प्रभावित व्यक्ति सं बातचीत करय कें लेल ईच्छुक होयतै ? उदाहरण के लेल, कि						

	कोनो व्यक्ति कुष्ठरोग लागल व्यक्ति सं बातचित करत ?						
५.	की लोक सब (कुष्ठरोग) सं प्रभावित भेल व्यक्ति कें घर जेबाक लेल ईच्छुक हेताह ? उदाहरण के लेल, कि कोनो व्यक्ति कुष्ठरोग लागल व्यक्ति के घर जाक चाय पियत ?						
६.	की अहां कें समाज कें लोक सब (कुष्ठरोग) लागल व्यक्ति कें परिवार कें सम्मान करतै ? उदाहरण के लेल, कि कोनो कुष्ठरोग लागल व्यक्ति के परिवार सं राय विचार मांगतै?						
७.	की (कुष्ठरोग) लागल व्यक्ति कें परिवार कें समाज में स्वीकार केल जायत ? उदाहरण के लेल, कि समुदायके लोक सब कुष्ठरोग लागल व्यक्ति के परिवार के समुदायके कामकाज मे आमन्त्रित करत ?						
८.	कि कुष्ठरोग लागल व्यक्ति के परिवार के सदस्य कियो दोसर के हमर घर मे कुष्ठरोग छै से कहैय मे सहज महसुस करतै ? उदाहरण के लेल, कि केकरो अपन दोस्त के ई कहैय मे आसान वा सहज महसुस हेतैय जे ओकर भाई या बहिन के कुष्ठरोग छै ?						
९.	की कोनो समुदाय कें व्यक्ति (कुष्ठरोग) लागल व्यक्ति सं विवाह करय लेल ईच्छुक हेताह ?						
१०	की कोनो समुदाय कें व्यक्ति (कुष्ठरोग) लागल व्यक्ति कें रिश्तेदार सं विवाह करय कें लेल ईच्छुक होयतै ? उदाहरण के लेल, कि कोनो कुष्ठरोग लागल व्यक्ति के भाई या बहिन सं विवाह करतै ?						
११.	की कोनों रोजगारदाता (कुष्ठरोग) लागल व्यक्ति कें काम पर रखबाक लेंल ईच्छुक होयतै ? उदाहरण के लेल, कि कोनो विधालय कुष्ठरोग लागल व्यक्ति के शिक्षक के काम देतैय ?						
१२.	की लोक सब (कुष्ठरोग) सं प्रभावित व्यक्ति सं भोजन खरीदय कें लेंल ईच्छुक हेताह ? उदाहरण के लेल, कि कोनो व्यक्ति कुष्ठरोग लागल व्यक्ति सं तरकारी किनतै ?						
१३.	लोक सब बात करैय बेर में व्यकित कें नाम कें सट्टा ओकरा (कुष्ठरोगी) कें नाम ल क कतेक बेर प्रयोग कयल जाइत अछि ? उदाहरण के लेल, राम प्रकाश के सट्टा ओकरा कुष्ठरोगी कहनाय?						

Appendix VI: Explanatory Model Interview Catalogue Community Stigma Scale

VI.I The English version of the EMIC-CSS

Item	Question	Yes	Possibly	No	Don't know	Score
		2	1	0	0	
1.	Would a person with [condition] try to keep others from knowing?					
2.	If a member of your family had [condition], would you think less of yourself, because of this person's problem?					
3.	In your community, does [condition] cause shame or embarrassment?					
4.	Would others think less of a person with [condition]?					
5.	Would knowing that someone has [condition] have an adverse effect on others?					
6.	Would other people in your community avoid a person affected by [condition]?					
7.	Would others refuse to visit the home of a person affected by [condition]?					
8.	Would people in your community think less of the family of a person with [condition]?					
9.	Would [condition] cause problems for the family?					
10.	Would a family have concern about disclosure if one of their members had [condition]?					
11.	Would [condition] be a problem for a person to get married?					
12.	Would [condition] cause problems in an ongoing marriage?					
13.	Would having [condition] cause a problem for a relative of that person to get married?					
14.	Would having [condition] cause difficulty for a person to find work?					
15.	Would people dislike buying food from a person affected by [condition]?					

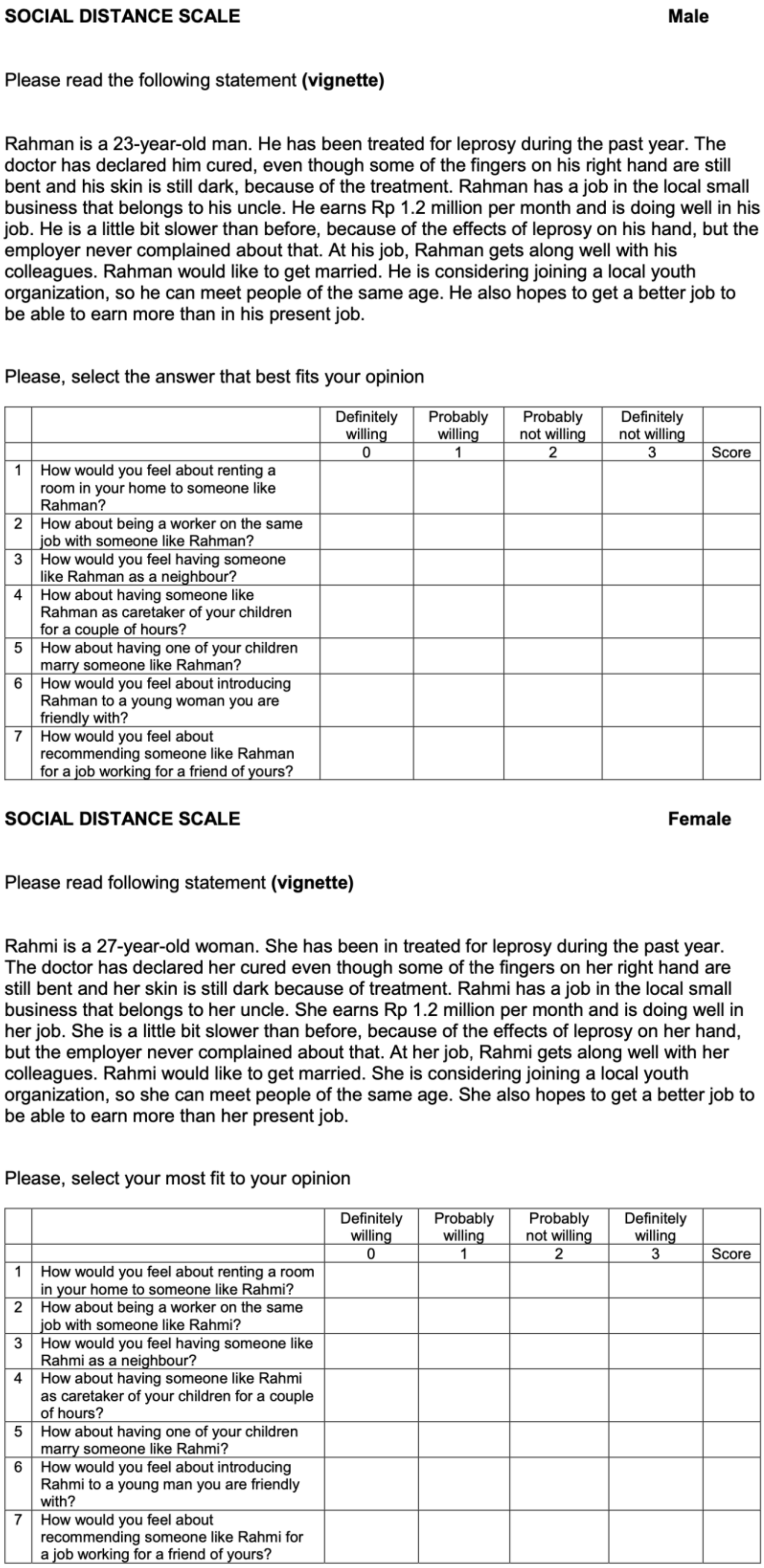
VI.II The Maithili version of the EMIC-CSS

अन्तर्वाता सम्पन्न होबएस ा पहिले कृपया कुनो प्रश्नसभक उत्तर छुटल अछि कि नै से चेक करब।
अनुसुचि ४ (इमिक कम्युनिटी स्टिग्मा स्केल (इमिक सिसिएस)
इमिक सिसिएस कुष्ठप्रभावित वाहेक अन्य सब लक्षित वर्गक लेल प्रयोग होईछै।

		हा	होब सकैया	नै	प्ता नै	प्राप्तांक
		२	१	०	०	
१	कि कुष्ठ प्रभावित व्यक्ति लागल रोगक बारेमे दोसरो लोक बुझए से चाहैत हेतै ?					
२	आहाक परिवारमे ककरो कुष्ठरोग लागल हुवे त, ओहि व्यक्तिक कारण ा शर्मिन्दगी महसुस कएने छी ?					
३	आहाक समुदायमे, कि कुष्ठरोग शर्मिन्दा वा लाजघीनक विषय अछि ?ा					
४	कि कुष्ठरोग लागल व्यक्तिके दोसर गोटे कम मानैछै ?					
५	ककरो कुष्ठरोग लागल छलै वा छै से जानकारी भेलाके बाद कि दोसरके प्रतिक्रिया नकारात्मक भ' जाईत हेतै ?					
६	कि समुदायक अन्य लोकसभमे कुष्ठ प्रभावित व्यक्तिके नजरअन्दाज करएके प्रवृति छै ?					
७	कि अन्य लोकसभ कुष्ठ प्रभावित व्यक्तिसभक घरमे जाएस ा इन्कार वा अस्वीकार करैत छै ?					
८	कि कुष्ठप्रभावित व्यक्तिक परिवारक सदस्यसभके दोसरसभ कम महत्व दैछै ?					
९	कि कुष्ठरोगक कारण परिवारमे समस्यासभ आएल करैत छै ?					
१०	परिवारमे ककरो कुष्ठरोग लागल हुवे त खुलासा करएके वारेमे चिन्ता रहैत छै ?					
११	कि कुष्ठरोग प्रभावित व्यक्तिके विवाह होबएमे समस्या होईछै ?					
१२	कि कुष्ठरोग व्यक्तिक वैवाहिक जीवन (विवाहक बादो) के लेल समस्या भेल करैत छै ?					
१३	कि कुष्ठप्रभावित व्यक्तिक नातेदार भेलाक कारण व्यक्तिके विवाह होबमे समस्या होईछै ?					
१४	कि कुनो व्यक्तिके कुष्ठरोग भेलेके कारण काम पाबएमे कठिनाइ होईछै ?					
१५	कि कुष्ठप्रभावित व्यक्तिस ा अन्य व्यक्तिसभ खाद्य पदार्थ किन नै मानैत छै ?					
					जम्मा	

Appendix VII: Social Distance Scale

VII.I The English version of the SDS



SOCIAL DISTANCE SCALE **Male**

Please read the following statement **(vignette)**

Rahman is a 23-year-old man. He has been treated for leprosy during the past year. The doctor has declared him cured, even though some of the fingers on his right hand are still bent and his skin is still dark, because of the treatment. Rahman has a job in the local small business that belongs to his uncle. He earns Rp 1.2 million per month and is doing well in his job. He is a little bit slower than before, because of the effects of leprosy on his hand, but the employer never complained about that. At his job, Rahman gets along well with his colleagues. Rahman would like to get married. He is considering joining a local youth organization, so he can meet people of the same age. He also hopes to get a better job to be able to earn more than in his present job.

Please, select the answer that best fits your opinion

		Definitely willing	Probably willing	Probably not willing	Definitely not willing	
		0	1	2	3	Score
1	How would you feel about renting a room in your home to someone like Rahman?					
2	How about being a worker on the same job with someone like Rahman?					
3	How would you feel having someone like Rahman as a neighbour?					
4	How about having someone like Rahman as caretaker of your children for a couple of hours?					
5	How about having one of your children marry someone like Rahman?					
6	How would you feel about introducing Rahman to a young woman you are friendly with?					
7	How would you feel about recommending someone like Rahman for a job working for a friend of yours?					

SOCIAL DISTANCE SCALE **Female**

Please read following statement **(vignette)**

Rahmi is a 27-year-old woman. She has been in treated for leprosy during the past year. The doctor has declared her cured even though some of the fingers on her right hand are still bent and her skin is still dark because of treatment. Rahmi has a job in the local small business that belongs to her uncle. She earns Rp 1.2 million per month and is doing well in her job. She is a little bit slower than before, because of the effects of leprosy on her hand, but the employer never complained about that. At her job, Rahmi gets along well with her colleagues. Rahmi would like to get married. She is considering joining a local youth organization, so she can meet people of the same age. She also hopes to get a better job to be able to earn more than her present job.

Please, select your most fit to your opinion

		Definitely willing	Probably willing	Probably not willing	Definitely willing	
		0	1	2	3	Score
1	How would you feel about renting a room in your home to someone like Rahmi?					
2	How about being a worker on the same job with someone like Rahmi?					
3	How would you feel having someone like Rahmi as a neighbour?					
4	How about having someone like Rahmi as caretaker of your children for a couple of hours?					
5	How about having one of your children marry someone like Rahmi?					
6	How would you feel about introducing Rahmi to a young man you are friendly with?					
7	How would you feel about recommending someone like Rahmi for a job working for a friend of yours?					

VII.II The Maithili version of the SDS

अनुसुचि ५ (सामाजिक दुरी स्केल

सामाजिक दुरी स्केल कुष्ठ प्रभावित व्यक्ति वाहेक अन्य सब लक्षित वर्गक लेल प्रयोग होईत अछि। स्थान वा लिङ्ग अनुसारक कथासभ प्रयोग क’ सकैछी ।

कृपया सहभागीक लिङ्गक आधारमे निचा उल्लेख कएल गेल कथा वाचन करब :

पुरुषके लेल	महिलाका लागि
राजकिसोर २३ वर्षक युवक अछि । ओ पछिला सालस ा कुष्ठरोगक उपचार करारहल अछि। डाक्टर हुनका रोग ठिक भ’ गेल बतौने अछि तैयो हुनक दहिना हातक किछु आगुरसभ टेढमेढ अछि आ ा दवाईक कारणे छालाक रङ्ग कारी भ’ गेल अछि । राजकिसोर अपन काकाक एकटा घरेलु व्यवसायमे काम करैत अछि । ओ महिनाक २५ हजार कमाईत अछि आ काजमे लगनशील सेहो अछि। ओकर रोगक कारण हातमे असर परलास ा काज करएके फुर्ति पहिलेके तुलनामे कनि कम भ’ गेल छै लेकिन रोजगारदाताके अहिस ा कुनो समस्या नै छै । कामक सन्दर्भमे राजकिसोर साथीसभसंगे रहैत अछि । ओकरा विवाह करएके मन छै । ओ एकटा स्थानिय युवा समूहमे आवद्ध होबए चाहैत अछि जतए ओकरे समूहक साथीसभ संलग्न छै । ओ एखनस ा बेसी तलब होबएबला नोकरी भेटत से आशावादी सेहो छै।	रजनी २७ वर्षक युवति अछि। ओ पछिला सालस ा कुष्ठरोगक उपचार करारहल अछि। डाक्टर हुनका रोग ठिक भ’ गेल बतौने अछि तैयो हुनक दहिना हातक किछु आगुरसा भ टेढमेढ अछि आ दवाईक कारणे छालाक रङ्ग कारी भ’ गेल अछि। रजनी अपन काकाक एकटा घरेलु व्यवसायमे काम करैत अछि। ओ महिनाक २० हजार कमाईत अछि आ काजमे लगनशील सेहो अछि। ओकर रोगक कारण हातमे असर परलास ा काज करएके फुर्ति पहिलेके तुलनामे कनि कम भ’ गेल छै लेकिन रोजगारदाताके अहिस ा कुनो समस्या नै छै। कामक सन्दर्भमे राजनी साथीसभसंगे रहैत अछि। ओकरा विवाह करएके मन छै। ओ एकटा स्थानिय युवा समूहमे आवद्ध होबए चाहैत अछि जतए ओकरे समूहक साथीसभ संलग्न छै। ओ एखनस ा बेसी तलब होबएबला नोकरी भेटत से आशावादी सेहो छै।

		एकदम चाहैछी	सम्भवत चाहैछी	सम्भवत नैचाहैछी	एकदम नै चाहैछी	
		०	१	२	३	स्कोर
१	आहााके ʿ?नामश्रै जेहन कुनो व्यक्तिके अपन घरमे भाडामे रह देब परल त केहन महसुस करबै ?					
२	?नामश्रै करहल काम जेहन काममे कामदार बनमे दोसरके केहन महसुस होईत हेतै से सोचने छी ?					
३	आहाक परोसी ा ʿ?नामश्रै जेहने व्यक्ति भेल त कि करबै ?					
४	ʿ?नामश्रै सनके व्यक्तिके यदि किछु समयके लेल आहाक ा बच्चाके देखभालके जिम्मेवारी लेबपरलै त आहा ा केहन महसुस करबै ?					
५	ʿ?नामश्रै जेहन कुनो व्यक्तिसंग आहाक बेटा वा बेटीक ा विवाह होबके बात भेलै त कि करबै ?					
६	आहासा ा परिचित युवतीसंगे ʿ?नामश्रै के परिचय कराबएके क्रममे केहन महसुस करबै ?					
७	आहााके अपन साथीभाइ मार्फत ʿ?नामश्रै सनके व्यक्तिके लेल नोकरीके सिफारिस करएपरल त केहन महसुस करबै ?					
					जम्मा	

Appendix VIII: Village areas in the quantitative study

Table A1. This information is part of the socio-demographic table of participants that have participated in the quantitative phase of this study (see Chapter 5.2.1). It contains information (the number and percentage) on the many villages in the Dhanusha, Mahottari, and Sarlahi districts, in Madhesh province, from where the community members originate.

	Participants (N)	**Percentage (%)**
Village		
Laliya	18	18
Bengasipur Thumhauna	12	12
Shree Nagar	9	9
Manara	8	8
Nawalpur	7	7
Durga Tole	7	7
Bhokteni	7	7
Kamat	6	6
Basantpur	5	5
Barhampuri	3	3
Mohangunj	2	2
Dharapani	1	1
Dhalkebar	1	1
Lohra	1	1
Juri Bajar	1	1
Sarshwar	1	1
Gorpar	1	1
Bishnu	1	1
Bengadavar	1	1
Lalgadh	1	1
Dhankaul	1	1
Bhediya	1	1
Ibarwa	1	1
Chuharba	1	1
Dumariya	1	1
Mahuliya	1	1
Gaushala	1	1

Appendix IX: Codebook

Table A2. Codebook developed during the qualitative data analysis of semi-structured interviews. This codebook includes the main themes from this study's conceptual framework that are essential to answering the RQ.

Themes	Sub-codes	Origin	Definitions
Semantic validity	Item understanding	Deductive	It can be suggested that the item was understood once the community members were able to provide answers to the items
	Item understanding after examples	Inductive	The items were understandable once examples from the QbyQ were used
	Clear repeat answer	Inductive	When community members were able to paraphrase the items in their own words
	Clear words in item	Inductive	When community members were able to provide an example or explanation to the given 'potentially difficult' term
Item validity	Item relevance	Deductive	The items are relevant to both the community members and their community
	Item irrelevance	Inductive	The items are irrelevant to both the community members and their community
	Item acceptability	Deductive	The items were acceptable to the community members and their culture; they felt comfortable answering the items
Operational validity	Questionnaire appropriateness	Deductive	The questionnaire was considered as good among the community members
	Questionnaire relevance	Deductive	The questionnaire is relevant to both the community members and their community
	Questionnaire irrelevance	Inductive	The questionnaire is irrelevant to both the community members and their community
	Uncomfortable in interview	Inductive	When community members felt uncomfortable during the interview process

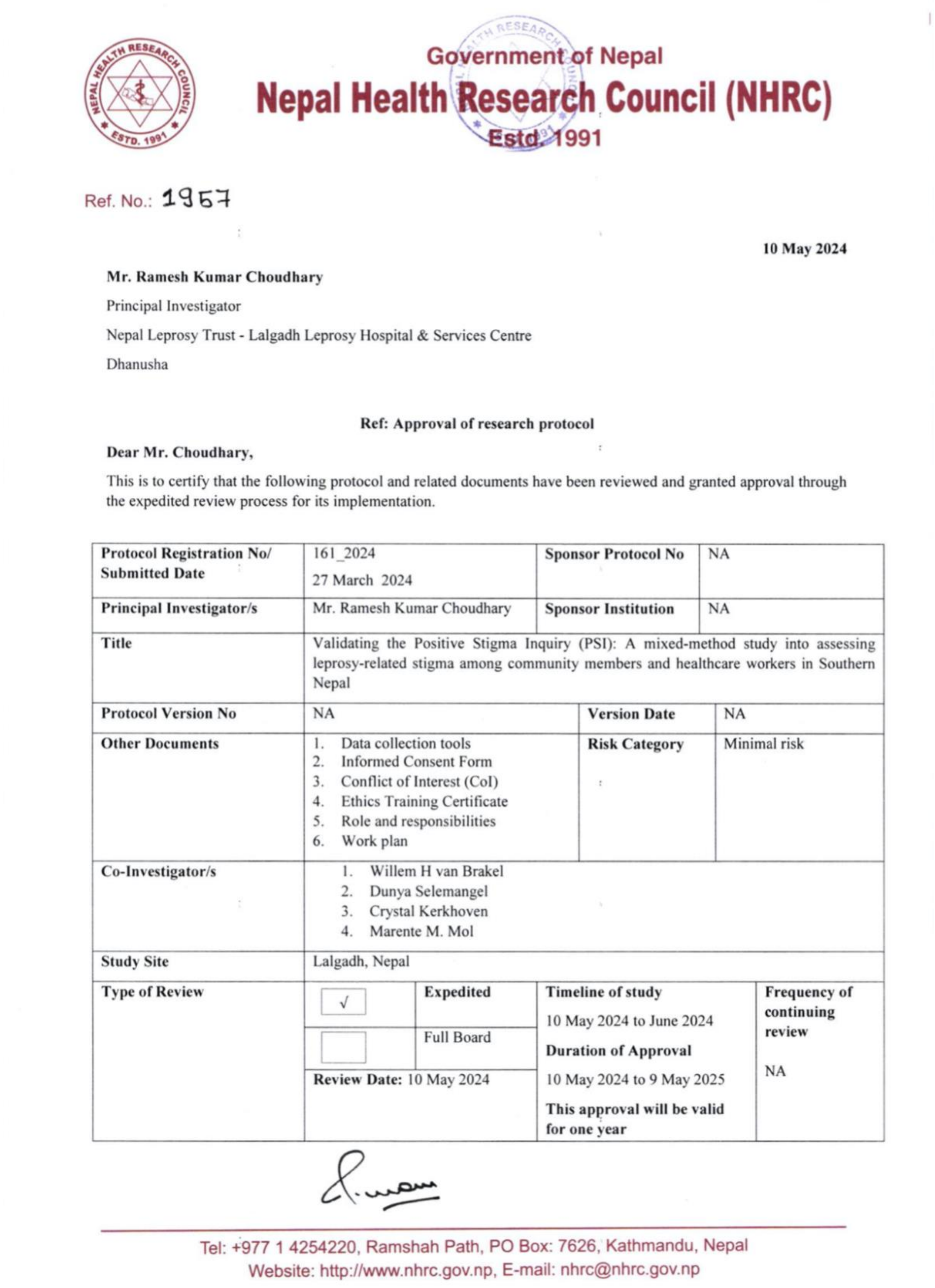
Appendix X: Discrepancies table for the PSI

Table A3. This table demonstrates the differences between the primary (English) and back-translated versions of the PSI. In addition, the solutions to the discrepancies are discussed and subsequently, the revised items are presented.

Item	English version	Back-translation	Discrepancies	Solution	Revised item
Title	Positive Stigma Inquiry (PSI) prototype	Positive Stigma Inquiry (PSI) Prototype	-	-	Positive Stigma Inquiry (PSI) Prototype
Subtitle	Scale for assessing community member health-related stigma	Scale for accessing community member health-related stigma	The term “accessing” differs from the term “assessing”. The term “member” was regarded as vague and not commonly used in the Maithili language to describe an individual in the community.	“Accessing” was an error and was corrected. “Member” was changed into “person”, or “people” if used as a plural. This way, there was a clearer understanding for both researchers and participants regarding the intended meaning of “community member”.	Scale for assessing community people health-related stigma.
1	Would a person with [condition] be willing to tell others about their condition?	Would an infected person be ready to tell others about their (situation)?	The term “person with (condition)” differs from “infected person”. The term “be ready” has a different meaning than the term “be willing”. The term “situation” is different from the term “condition”.	“Infected” was a typing error and was corrected into “affected”. “Be ready” was changed into “be willing” and was included in the revised item. Both “condition” and “situation” translate to the same term in Maithili language.	Would an affected person be willing to tell others about their (situation)?
2	Would a community member feel comfortable living near a person with [condition]?	Would a community member feel comfortable being around a person with (situation)?	The term “being” is different from the term “living”.	The on-site supervisor fluent in Maithili was asked to read the Maithili version of this item and translate it into English. The term “living” was already accurately translated from English to Maithili. Because of this, “being” was corrected into “to live”.	Would a community person feel comfortable to live around a person with (situation)?
3	After finding out that a person has [condition], would a community member have the same (or more) respect towards this person?	After finding out the (situation) of a person, would a community member have the same (or more) amount of respect towards the infected person?	The term “person with (condition)” differs from “infected person”.	“Infected” was a typing error and was corrected into “affected”.	After finding out the (situation) of a person, would a community member have the same (or more) amount of respect towards the affected person?
4	Would other people in your community be willing to interact with a person affected by [condition]?	Would other people in your community be comfortable to interact with a person affected by (situation)?	-	-	Would other people in your community be comfortable to interact with a person affected by (situation)?
5	Would people be willing to visit the home of a person affected by [condition]?	Would people in your community be willing to visit the house of the affected person (situation)?	The item in the questionnaire, which referred to an "affected person (situation)," maintained the same meaning in both the Maithili and English versions. However, the grammar of the back-translation was not accurately expressed in English.	No changes were made.	Would people in your community be willing to visit the house of the affected person (situation)?
6	Would people in your community respect the family of a person with [condition]?	Would people in your community respect the family of a person with (situation)?	-	-	Would people in your community respect the family of a person with (situation)?
7	Would the family of a person with [condition] be accepted in the community?	Would the family of a person with (situation) be accepted in your community?	-	-	Would the family of a person with (situation) be accepted in your community?

8	Would the family member of a person with [condition] feel comfortable talking about it to their friends?	Would the family member of a person with (situation) feel comfortable to talk about it with their friends?	-	-	Would the family member of a person with (situation) feel comfortable to talk about it with their friends?
9	Would a community member be willing to marry a person with [condition]?	Would a community member be willing to marry a person with (situation)?	-	-	Would a community member be willing to marry a person with (situation)?
10	Would a community member be willing to marry a relative of a person with [condition]?	Would a community member be willing to marry a relative of person with (situation)?	-	-	Would a community member be willing to marry a relative of person with (situation)?
11	Would an employer be willing to hire a person with [condition]?	Would an employer be willing to hire a person with (situation)?	-	-	Would an employer be willing to hire a person with (situation)?
12	Would people be willing to buy food from a person affected by [condition]?	Would people be willing to buy food from a person with (situation)?	-	-	Would people be willing to buy food from a person with (situation)?
13	How often is the name of [condition] used instead of the person's own name when people talk about him/her?	How often a person is called by their (situation) instead of their name when people talk about him/her?	In addressing the stigma associated with leprosy, individuals may commonly use the term "leper" to refer to a person affected by leprosy. In this research, rather than stating "their (condition/situation)", we will utilize the Maithili translation of the English term "leper".	Replacing the phrase "by their (situation)" with "leper".	How often a person is called "leper" instead of their own name when people talk about him/her?
14	Would the care of a patient who has/had [condition] be considered a "respectable job"?	Would caring a patient with (situation) be considered a "respectable job"?	-	-	Would caring a patient with (situation) be considered a "respectable job"?
15	At the health facility, would health care providers be comfortable touching someone with [condition]?	At the health care centre, would health care providers be comfortable touching a person with (situation)?	-	-	At the health care centre, would health care providers be comfortable touching a person with (situation)?
16	Are patients with wounds or disabilities due to [condition] treated in the same treatment room or ward as other patients?	Are patients with wounds or disabilities due to (situation) treated in the same treatment room or ward as other patients?	-	-	Are patients with wounds or disabilities due to (situation) treated in the same treatment room or ward as other patients?
17	Would you use different protective measures when treating patients with [condition] as you would for patients with other infectious diseases? (e.g., tuberculosis)	Would you use other protective measures while treating patients with (situation) as you would for patients with other infectious diseases? (e.g., tuberculosis)	-	-	Would you use other protective measures while treating patients with (situation) as you would for patients with other infectious diseases? (e.g., tuberculosis)
18	Would you feel comfortable diagnosing or managing [condition] cases at your health care facility?	Would you feel comfortable diagnosis or managing (situation) cases at your health care centre?	-	-	Would you feel comfortable diagnosis or managing (situation) cases at your health care centre?

Appendix XI: Ethical approval



Government of Nepal

Nepal Health Research Council (NHRC)

Estd. 1991

Ref. No.: 1957

10 May 2024

Mr. Ramesh Kumar Choudhary
Principal Investigator
Nepal Leprosy Trust - Lalgadh Leprosy Hospital & Services Centre
Dhanusha

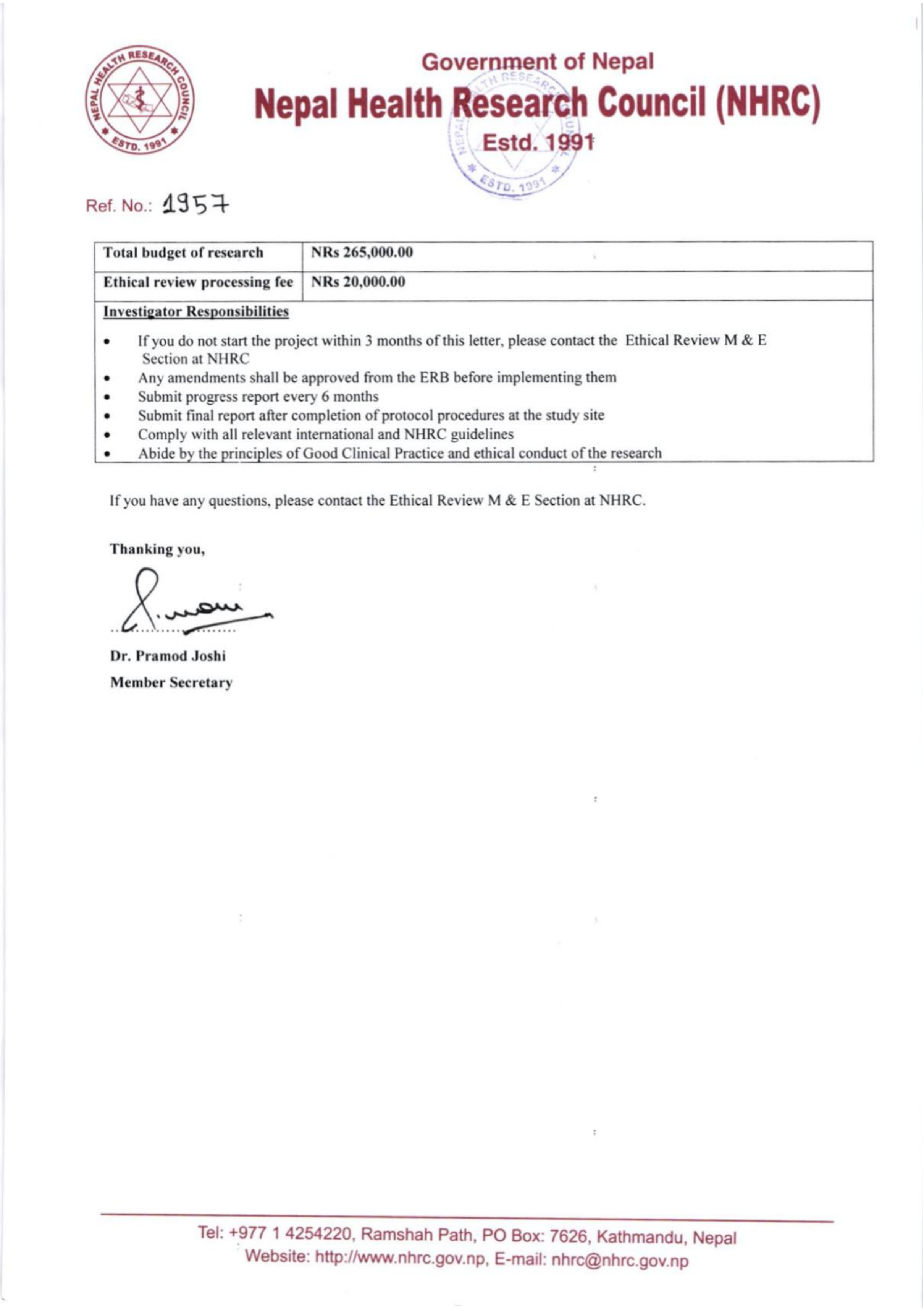
Ref: Approval of research protocol

Dear Mr. Choudhary,

This is to certify that the following protocol and related documents have been reviewed and granted approval through the expedited review process for its implementation.

Protocol Registration No/ Submitted Date	161_2024 27 March 2024	**Sponsor Protocol No**	NA
Principal Investigator/s	Mr. Ramesh Kumar Choudhary	**Sponsor Institution**	NA
Title	Validating the Positive Stigma Inquiry (PSI): A mixed-method study into assessing leprosy-related stigma among community members and healthcare workers in Southern Nepal		
Protocol Version No	NA	**Version Date**	NA
Other Documents	1. Data collection tools 2. Informed Consent Form 3. Conflict of Interest (CoI) 4. Ethics Training Certificate 5. Role and responsibilities 6. Work plan	**Risk Category**	Minimal risk
Co-Investigator/s	1. Willem H van Brakel 2. Dunya Selemangel 3. Crystal Kerkhoven 4. Marente M. Mol		
Study Site	Lalgadh, Nepal		
Type of Review	☑ **Expedited** ☐ Full Board **Review Date:** 10 May 2024	**Timeline of study** 10 May 2024 to June 2024 **Duration of Approval** 10 May 2024 to 9 May 2025 **This approval will be valid for one year**	**Frequency of continuing review** NA

Tel: +977 1 4254220, Ramshah Path, PO Box: 7626, Kathmandu, Nepal
Website: http://www.nhrc.gov.np, E-mail: nhrc@nhrc.gov.np



Government of Nepal

Nepal Health Research Council (NHRC)

Estd. 1991

Ref. No.: 1957

Total budget of research	**NRs 265,000.00**
Ethical review processing fee	**NRs 20,000.00**

Investigator Responsibilities

- If you do not start the project within 3 months of this letter, please contact the Ethical Review M & E Section at NHRC
- Any amendments shall be approved from the ERB before implementing them
- Submit progress report every 6 months
- Submit final report after completion of protocol procedures at the study site
- Comply with all relevant international and NHRC guidelines
- Abide by the principles of Good Clinical Practice and ethical conduct of the research

If you have any questions, please contact the Ethical Review M & E Section at NHRC.

Thanking you,

Dr. Pramod Joshi

Member Secretary

Tel: +977 1 4254220, Ramshah Path, PO Box: 7626, Kathmandu, Nepal
Website: http://www.nhrc.gov.np, E-mail: nhrc@nhrc.gov.np

Appendix XII: AI statement

In this study, one artificial intelligence (AI) tool, called Quill Bot, was employed to improve the language used in the sentences. Quill Bot does not suggest additional prompts or modify the structure of the sentences, but it does provide synonyms for words. Initially, I wrote the sentences myself in my own words. Then, I pasted my own sentence into Quill Bot to see if there were any better alternatives (or synonyms) for certain words that could potentially be used instead. For example, in the discussion I initially wrote the following sentence (in my own words): *'One essential strength is that this study used a validated theoretical framework, because it has been used in previous validation studies.'* After inserting this phrase into Quill Bot, the new sentence reads: *'One fundamental strength is that this study used a validated theoretical framework, as it has been employed in previous validation studies.'* Quill Bot provided multiple alternatives (or synonyms) for the words '*essential'*, *'because'*, and *'used'*. As you can see, I have changed these words into *'fundamental'*, *'as'* and *'employed'*, to make the sentence more professional. Another example is the first sentence from the summary: *'Health-related stigma can be defined as a process in which persons with certain health conditions experience negative perceptions and attitudes from society.'* Quill Bot provided alternatives or synonyms for the words *'can be'*, *'experience',* and *'negative'*, and were therefore changed into: *'Health-related stigma is defined as a process in which persons with certain health conditions face adverse perceptions and attitudes from society.'*